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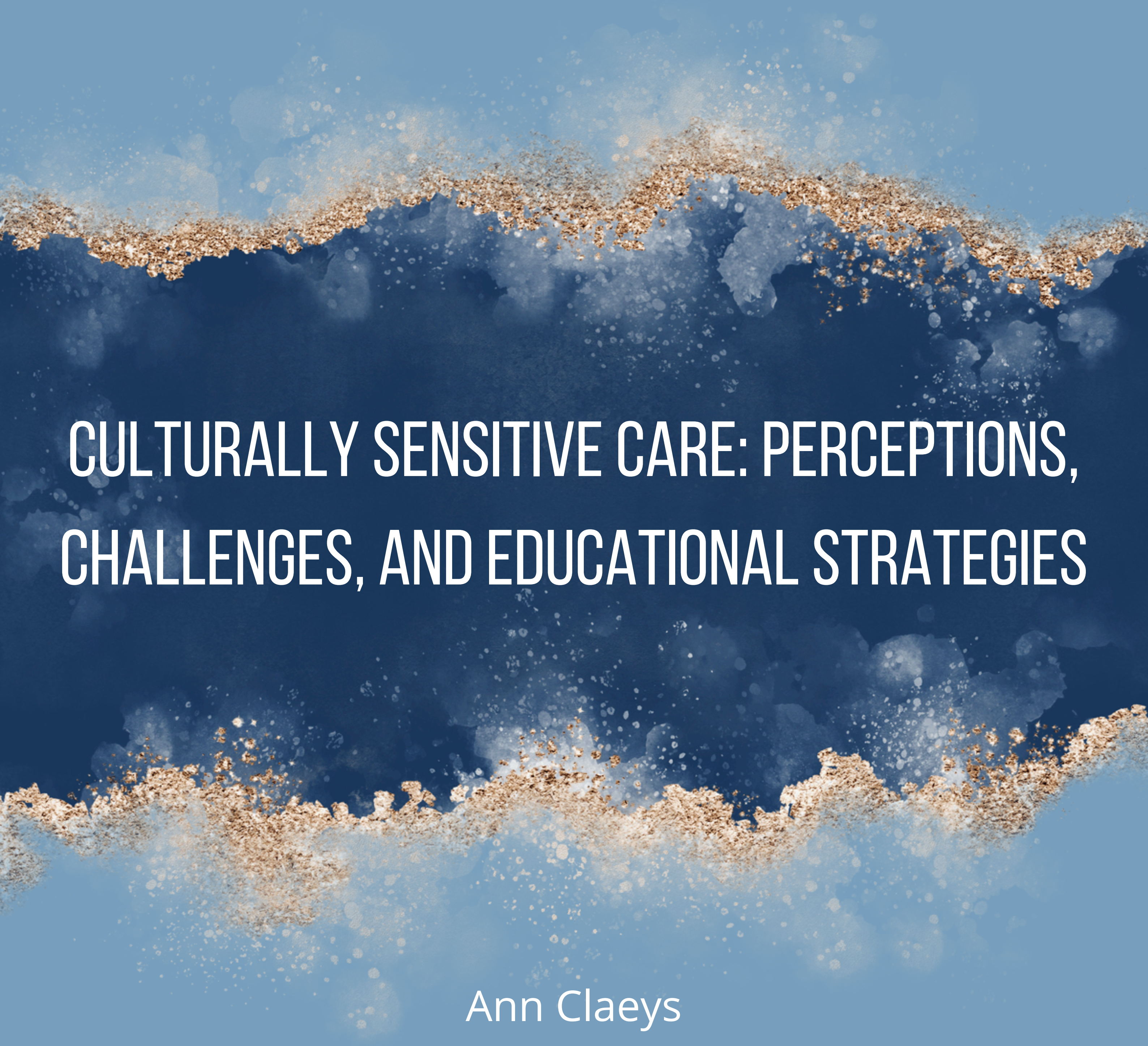

CULTURALLY SENSITIVE CARE: PERCEPTIONS, CHALLENGES, AND EDUCATIONAL STRATEGIES

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> *"We operate in the world mostly on autopilot,*
>
> *doing the same things today that didn't work yesterday."*
>
> Dr. Gordon Livingston

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Chapter 1: Introduction

This dissertation explores the theme of culturally sensitive care, studying it from the perspectives of both healthcare providers and informal carers. The exploration of these viewpoints leads to the development, implementation, and evaluation of an educational module designed to increase cultural awareness among nursing students. The dissertation begins by outlining the background and context of the study. The methodology is then explained, including the research paradigm, design, and the positionality of the researcher. The following four chapters present the research papers included in this dissertation. The dissertation concludes with a critical discussion on the findings. The implications are discussed, and recommendations for further research, policy, and practice are formulated.

In this introduction three main sections can be found. In the first section, the background is presented. In the second section, the research problem is outlined. In the third section, the research questions are presented, and an overview is given of this work and the following chapters.

1.1 Evolving care needs and healthcare system challenges

In the first section of this introduction, the background is outlined to understand the context of culturally sensitive care, by situating several demographic and societal trends. These evolutions have reshaped the profile of persons in need of care in Belgium, presenting new challenges and opportunities for the healthcare system to adapt and respond to the evolving needs of its population. This section describes the changes in the profile of the patient and how increased care complexity and diversity among patients have influenced care needs. It also explores the shifting position of patients within the care system. Finally, the section addresses the limitations of current fragmented and uniform care models, advocating for more integrated and culturally sensitive care solutions.

Central in care is the person in need of care. Depending on the sector, this individual may be referred to as a patient, client, care recipient, service user, or resident (Neuberger & Tallis, 1999). For the purposes of this dissertation, most often the term 'patient' will be used, because several of the studies discussed in this dissertation were conducted in the field of healthcare and healthcare providers. It is important to note that this patient is viewed from a holistic perspective, meaning that they may have broader needs beyond medical or physical care, including social care, welfare, housing needs, spiritual, existential questions, etc. (Wong et al., 2022). This perspective recognizes that patients may rely on a wide range of ‘supporters’ such as informal carers or formal services from both health and welfare sectors, emphasizing that my research is not limited to medical care alone.

1.1.1 Changes in the profile of the patient

In recent decades, Belgium, like other countries, has undergone considerable transformations in the profile of the patient. First, there is an increase in heavier and more complex care needs, due to the ageing population, together with a rise in age-related and chronic conditions, requiring more intensive and specialized long-term care (Castellana et al., 2021; Li et al., 2021; Mitchell & Walker, 2020). Second, there are important changes in the position of the patient in the healthcare system, e.g. the formal recognition of patient rights, ensuring that individuals receive care that respects their autonomy, dignity, and preferences (Kuosmanen et al., 2021). Also, the deinstitutionalisation of care has become more prominent, emphasizing care within the community and home settings rather than in institutional environments, with a growing pressure on informal carers (D'herde et al., 2021). Thirdly, there is an increase in population diversity, partly under the influence of migration and globalization (UN Migration, 2019). This diverse population also brings varied health profiles and care needs, requiring different approaches and personalized care to effectively meet the unique needs of diverse patients (Vertovec, 2007).

Increased and more complex care needs

An ageing population, together with a rise in age-related and chronic conditions, has led to increased and more complex care needs.

An ageing population

Belgium, like many countries worldwide, is experiencing a trend of an increasingly ageing population. This is due to a rising life expectancy combined with declining birth rates, resulting in a growing number of older persons. Globally, the average life expectancy was 47 years in 1950, 67 years in 2000 and has increased since then to 73 years in 2019 (Torres, 2019; WHO & Global Health Observatory, 2020). In a global context, the most rapidly ageing populations are found in low- and middle-income countries (Mitchell & Walker, 2020).

In Belgium, 20% of the population was 65 years or older in 2023, and this percentage is expected to continue rising. The ageing population trend will be particularly pronounced over the next years as the baby boom generation reaches the age of 65 and older. This indicates that a large group of people will soon retire, impacting the workforce, pension spending and care expenditures in the future (Statistiek Vlaanderen, 2023). The demographic shift of ageing is also pronounced in the segment of persons aged 80 and above, which is growing faster than other age cohorts and is projected to increase significantly by 2100 (Statbel, 2024).

Increased age-related and chronic conditions.

The ageing of a population is more than just an increase in average life expectancy or the number of older persons. It is a demographic transition with specific societal implications, such as an increase in age-related and chronic conditions, a higher number of people needing care, and having more complex care needs. As life expectancy rises, more individuals are living longer with conditions including neurodegenerative, cardiovascular, musculoskeletal or immune system disorders, such as dementia, heart disease, arthritis, diabetes and cancer (Jaul & Barron, 2017; Li et al., 2021; Mitchell & Walker, 2020). Ageing is a determining factor behind various of these morbidities, as the prevalence of these conditions, including frailty, rises with and increasing age. Frailty, a result of the ageing process and chronic diseases, leads to higher risks of physical and cognitive decline, disability, and decease (Castellana et al., 2021). Dementia also has an higher prevalence with higher age, with a notable increase in prevalence after the age of 70 (Culberson et al., 2023). These chronic conditions often require long-term management and continuous care, challenging the healthcare system. In general, this trend translates to higher healthcare costs, increased demand for medical and care services, and an increased need for specialized healthcare providers (Mitchell & Walker, 2020). Healthcare infrastructure needs to accommodate the growing number of persons with complex care needs, which involves expanding chronic care, improving disease management programs, and providing support for informal carers (Jaul & Barron, 2017). For patients, managing multimorbidity often requires a coordinated approach involving different healthcare providers, frequent follow-up, and adherence to complex treatments. The physical and mental impact of living with chronic conditions asks for comprehensive holistic care strategies that address both physical and mental health needs (Culberson et al., 2023; Jaul & Barron, 2017; Mitchell & Walker, 2020).

Projections indicate that age-related and chronic conditions will continue to increase with the ageing wave of baby boomers (Mitchell & Walker, 2020). As age-related and chronic conditions rise, it is important to note that healthcare providers and the public health community must be sensitive to the diverse needs of the older population, recognizing that not every older person is a chronic patient, and empowering the potential of each individual person. This emphasizes the need for adaptable and sensitive healthcare solutions (Timonen & Lolich, 2020). To conclude, not only the amount of potential persons in need of care, but also the complexity of care needs is increasing. This makes care needs more complex and requires additional competences from healthcare providers and a healthcare structure that is ready to accommodate these needs.

Changed position of the patient in the care system

The role of the patient in the care system has shifted due to the patient's emancipation and the deinstitutionalization of care, placing greater pressure on informal carers.

Emancipation of the patient

In recent decades, the position of patients has undergone important transformations, challenging the traditional relationship between patients and healthcare providers. One of those changes in Belgium has been the law on patient rights, established in the 2002 legislation and recently amended in the 2024 law with several new principles. For example, the ‘obligation to cooperate’ was reformulated to create more equality between the patient and the healthcare provider, and with regard to the ‘right to quality of care’, the patient has the right to express individual preferences and needs (Belgisch Staatsblad, 2024). These legal frameworks ensure that patients have the right to be fully informed about their medical conditions, results of examinations and options of treatment, empowering them to make decisions about their own healthcare. This shift, which is part of an international trend, aims to foster a more collaborative relationship between patients and healthcare providers, moving away from the paternalistic model where doctors made decisions, with little patient or paramedic input towards a model of shared decision-making. Patients now have greater autonomy and can be active participants in their care, together with a multidisciplinary team (Kuosmanen et al., 2021; Molina-Mula & Gallo-Estrada, 2020).

In the recent years, the digitalisation of healthcare has further empowered patients, providing them with unprecedented access to both correct and incorrect medical information. Social media, online videos, and “Dr. Google" have transformed how patients educate themselves about health issues (Burzyńska et al., 2023; Plugmann & Plugmann, 2021). While this access to information can enhance patient knowledge and engagement, it also presents challenges, such as the risk of misinformation (Mukherjee et al., 2022). Nevertheless, the overall impact is that it makes patients more informed and involved in their healthcare trajectory (Botrugno, 2021). Evolutions within various specific healthcare domains, such as mental health and palliative care, have also contributed to this emancipatory shift. These fields have seen advancements that address the specific needs of patients more effectively, providing tailored care and support (Arias-Casais et al., 2020; Darcis et al., 2022). The focus on personalized care plans and the inclusion of patient preferences have become more central.

Deinstitutionalisation of care, with an increased pressure on informal carers

Additionally, there has been a growing international trend towards the deinstitutionalisation of care, with a shift from residential care (i.e. hospital-based care or in nursing homes) to ambulatory and home-based care by integrating healthcare into the community. The deinstitutionalisation of care promotes support within one's living environment, fostering independence and enabling patients to stay at home as long as possible (Darcis et al., 2022). Because this approach aims to foster social inclusion and reduce pressure on residential care facilities, it necessitates a well-organized and accessible home care infrastructure (Donder et al., 2023; Steyaert, 2014). The deinstitutionalisation of care has evolved significantly over the years. In the 1960s and 1970s, there was increasing opposition to institutionalization, especially in mental health care. The start of actual 'de-institutionalization' was in the 1980s, moving from residential care to community-based options, integrating professional care through home and ambulatory services, and requiring local healthcare providers' collaboration. Later developments emphasized 'care *by* society', focusing on informal carers like volunteers and family members (Donder et al., 2023; Steyaert, 2014). More recently, a new phase has emerged, as seen in the Netherlands with the Social Support Act, but also in Flanders with policy programs such as caring communities, which reduces professional care in favour of informal and outpatient care. Unlike previous shifts driven by the opposition to residential care, the most recent change is motivated by perceived inefficiencies in the residential care sector, leading to significant care budget cuts and stricter eligibility requirements (Berkers et al., 2021; Steyaert, 2014).

In Belgium, as in other countries, policy relies more and more on informal carers, who are facing increasing pressure and responsibilities. Informal caregiving - care and support provided by people based on a personal relation with the person who needs care - often involves care assistance with daily activities such as mobility, dressing, bathing, feeding, and instrumental or administrative activities like bill-paying, shopping, cooking, medication management, and providing transportation. It can also include emotional support and help in managing chronic conditions or disabilities (Culberson et al., 2023). Informal caregiving can be physically and emotionally demanding, especially without adequate support (D'herde et al., 2021). As medical needs evolve, informal carers may face increasing duties and challenges, resulting in stress that can impact their own physical and emotional health, as well as their capacity to work in a paid job and maintain social relationships (Culberson et al., 2023). In Belgium, as in other countries, the demographic shift towards an older population has resulted in a parallel increase in the average age of informal carers (Bom & Stöckel, 2021; D'herde et al., 2021). Many carers, often middle-aged or older, balance caregiving responsibilities with paid jobs, managing their households, and addressing their own age-related health concerns (Barbosa et al., 2020; Bom & Stöckel, 2021; Volckaert et al., 2021). The transition from hospital-based care to home-based care has also led to a shift in the coordination of care, a responsibility that now more often falls to the informal carer. The increasing amount and complexity of informal caregiving tasks underscore the importance of recognizing and supporting informal carers (Schneider et al., 2015).

A more diverse population

A third important change in the profile of the patient is linked with the increased diversity within current society. In this context, ‘migration’ represents (just) one facet of diversity. Migration and globalization have led to an increasingly diverse population, which in turn is impacting healthcare needs and expectations (King, 2019). Although everyone is ethnic, everyone has a culture, and each member of society contributes to diversity, the concepts of 'ethnicity,' 'culture,' and 'diversity' are in today's society most often primarily associated with individuals with a migration background (Torres, 2019). Migration background, and therefore the related diversity based on origin, is then mainly attributed to non-European non-white migration, encompassing both past and current migration and non-white religion (Ang et al., 2022). This dissertation will use the term 'person with a migration background', recognizing that the person may not have experienced own migration, but that migration took place in the family history (Karaman & Christian, 2020; Moosavi, 2015). In addition, ‘person of colour’ will also be used, taking into account that this is a collective term used in white societies for everyone who is non-white, recognizing the sociopolitical connotation and limitations of this term. The use of the term persons of colour as non-white also leads to the use of the term ‘white person’. When using this term, we again recognize the limitations of this term, but also the underlying fact of whiteness as a system. The following sections will explore the various terms used in more detail. When discussing topics like diversity, ethnicity, or migration, it is important to recognize the evolving nature of language and terminology, which reflects changing attitudes over time. This dissertation is written in a time when the terms mentioned are commonly used and accepted.

Migration and globalisation

Demographic growth in Belgium is currently primarily driven by international migration. Since the 2000s, the migration balance is the main driver of population growth, surpassing the natural balance (births minus deaths). As of 2022, 66.6% of the Belgian population had a Belgian background, while 20.6% were Belgians with a foreign background, and 12.8% were non-Belgians (Statbel, 2022).

The group of Belgians with a foreign background is very diverse:

- 49.6% did not hold Belgian nationality as their initial registered nationality but have acquired it since.
- 50.4% initially held Belgian nationality, comprising:
    - 20.6% with both parents possessing a foreign first registered nationality,
    - 29.8% with one parent possessing a foreign first registered nationality (Statbel, 2022) .

Nationality refers to a person's legal affiliation with a specific country or nation-state, involving citizenship and the associated rights, duties, and privileges. Individuals can have dual or multiple nationalities due to various factors such as parentage, immigration, or naturalization (FOD Justitie, 2024). Projections suggest the above mentioned trend will persist, with net migration becoming the primary driver of population growth by 2040 (Statbel, 2022). Global challenges, such as wars and conflicts or climate change, are important factors that are expected to increasingly drive global migration in the future (Moore & Wesselbaum, 2023; Scholten, 2022). Migration background refers to an individual's or their family's history of moving from one country or region to another. This term often describes immigrants or their descendants, highlighting the impact of migration on identity and life (Scholten, 2022). In this way, migration is not only a personal life event, but it becomes a family story or even a story across generations in society.

Globalization has intensified and transformed international migration flows, challenging traditional boundaries between sending and receiving countries. Trends such as the expansion of international trade, development of a global economy, and innovations in information and communication technology have increased international mobility (Scholten, 2022; Torres, 2019). As Marsella (2009) states: *"Demographic changes that are occurring are shaping a new global profile within and among nations. Consider these demographic realities: Five of six people in the world are non-Caucasian. The total Caucasian populations of the United Kingdom, Ireland, Germany, all the Scandinavian countries, Holland, Belgium, and Luxembourg is less than the population of Indonesia."* (Marsella, 2009, p.125). Globalisation is shaping a new and diverse reality that cannot be ignored. In the globalised world, transnationalism involves processes spanning two or more nation-states, with actors from both state and society spheres. While not all migrants are transnational, those who are maintain connections with multiple cultures simultaneously. This phenomenon has become more pronounced since the 1980s due to increased mobility and technological advancements (Torres, 2019).

Diversity by origin

Brussels, Belgium's capital, is an example of societal diversity with a population of about 1,208,542 individuals from 182 nationalities. This diversity comes from historical migration waves, including labour migration, family reunification, and refugee resettlement. Current trends like student mobility and intra-EU migration further contribute to this diversity, with 71% of Brussels' residents having roots in foreign origins (UN Migration, 2019). Diversity encompasses the differences between people in a society and refers to all aspects in which people differ from each other. Diversity is about the biological, socio-cultural, and social differences that can experienced by living together in a society. Diversity is also about combined differences between people: demographic characteristics and personal characteristics, such as age, religion, gender, sexual diversity, ethnic diversity, but also physical properties (diversity in capabilities or limitations), and also about differences in general appearance, characters, level of education, organizational culture, etc. (Vertovec, 2007). In this PhD, I will focus on diversity by origin. UNESCO (2001) describes the added values of cultural diversity: "As a source of exchange, innovation and creativity, cultural diversity is as necessary for humankind as biodiversity is for nature. In this sense, it is the common heritage of humanity and should be recognized and affirmed for the benefit of present and future generations." (UNESCO, 2001)

A diverse society includes various cultural, ethnic, religious, and social groups within a community or nation. Diversity acknowledges variety without implying any specific level of interaction (Vertovec, 2007). However, current society cannot be labelled anymore as a diverse society, yet rather as a superdiverse society. A superdiverse society has a higher level of diversity across multiple dimensions such as ethnicity, religion, language, lifestyle, and socioeconomic status. It recognizes that traditional categories of diversity are insufficient to capture the complexity of social identities and interactions (Vertovec, 2007). In addition to recognizing the presence of diversity within a society, various concepts can provide insight into the interactions within that diverse society. An inclusive society ensures that all individuals and groups, regardless of background, have equal opportunities to participate in all aspects of social, economic, and political life. It emphasizes removing barriers to participation and combating discrimination, going beyond a multicultural society (e.g. recognizes the diversity without encouraging interaction) or a intercultural society (e.g. encourages interaction between different cultural groups to foster mutual understanding and cooperation, while respecting cultural differences) (Ratcliffe, 2004).

Culture and ethnicity

Culture encompasses the beliefs, behaviours, customs, arts, institutions, and all other products of human work and thought that characterize a community or society. It includes language, religion, cuisine, social habits, music, and arts, and can cross national and ethnic boundaries (Birukou et al., 2013). Culture can be seen a backpack that people carry throughout their lives, filled with the values and experiences they have been socialized into. The content of this 'backpack' is not fixed and can change over time, and therefor culture is dynamic (Torres, 2019). In the example of religion, it is crucial to note that within any main religion, there are numerous movements. Additionally, regional and local contexts influence interpretations, resulting in a diversity of understandings even within the same area. Moreover, each individual contributes their personal interpretation to this complexity (Roccas, 2005). Therefore, an individual can identify with a particular culture or religion, providing insights into their values, norms, and beliefs. However, it is important to emphasize that there will always be regional and, importantly, personal differences and interpretations.

Ethnicity is a social categorisation that refers to a group of people who share common cultural traits, language, practices, and often a geographic origin. Ethnic groups are characterized by a shared cultural heritage and identity. From a social constructivist perspective, ethnicity involves three main components: external identification of a group as ethnic, internal identification by group members, and distinctive behaviour patterns (Gelfand, 2003). Ethnicity plays a crucial role in shaping personal and collective identity, providing a sense of belonging (Torres, 2019). The accuracy of classification of ethnicity, such as in hospital records, often falls short in comparison to self-reported ethnicity, particularly for non-White groups (Saunders et al., 2013). However, ethnicity is just one facet of identity, interacting dynamically with other aspects such as nationality, religion, gender, socioeconomic status, individual experiences, etc (Robards et al., 2020).

'Race' is a social construct used to categorize individuals based on physical traits such as skin colour or facial features. It is scientifically proven that there are no distinct human races (Goldberg, 2018). Categorizations based on 'race' lack genetic or biological foundation but are still used for sociopolitical agendas. Additionally, the term 'racism' incorporates reference to 'race'.

In Belgian and Flemish society, words such as cultural differences, ethnocultural diversity, cultural sensitivity, ..., are used without clear definition or consideration of the nuances, differences or interpretations. People often use these words to refer to who or what is 'the other'. The term 'migrant' (or 'allochtoon' in Dutch) refers to individuals with a migration background from 'non-Western' countries, encompassing several generations and various characteristics that mark them as outsiders (Charkaoui, 2019). This, and similar categorizations, imply an inherent inferiority, with expectations for migrants to adapt to the dominant culture without ever being fully accepted, as it is illustrated in this description:

> *"A migrant is, in the dominant collective imagination, any person with a migration background from a 'non-Western country', spanning from the first to approximately the fourth generation. It includes any person with a skin colour darker than the palest pink, and every Muslim, also including converts without a migration background. The migrant is seen as a perpetual outsider, and for some, an intruder. The term 'migrant' creates a*

> *category that is explicitly or implicitly considered inferior. A migrant can still upgrade themselves by adapting to 'our' (read: superior) culture, but they will never become truly 'native'. If the migrant does not make enough effort to adapt, there will be consequences. Does she want to wear a headscarf? Then there is no place for her in our schools or workplaces. Does he cook 'exotic' food? Then that is enough for a landlord to deny him an apartment."* (Charkaoui, 2019, p.27).

Diverse care needs

It can be assumed that a more diverse society leads to more diverse care needs. For particular groups, it is crucial to address specific care needs, for example such as those associated with a traumatic refugee experience or related to immigration (Mårtensson et al., 2020; Méroc et al., 2019). For some conditions, a higher prevalence can be observed in a certain ethnicity, although the underlying causes for this have not always been sufficiently studied. For example, dementia and diabetes appear to have a higher prevalence among non-Western immigrants (Bagger et al., 2021; Bennet et al., 2021; Parlevliet et al., 2016). Moreover, health inequalities due to social exclusion have been extensively demonstrated (Aylward et al., 2021; Blom et al., 2016; Chukwueke et al., 2022; Eneanya et al., 2022; Stennett & Tsakos, 2022). It is important to view this exclusion and the identified health inequalities from an intersectional lens. The identity of an individual person can be seen as an intersection of various aspects of that identity. If a person experiences exclusion or discrimination because of one or more aspects of his identity, the exclusion can be reinforced at the intersection of those aspects, which can influence the needs of that person (Robards et al., 2020). On top of these health inequalities, it is crucial for healthcare providers to adequately detect and address issues of discrimination, racism, and exclusion (Zemouri et al., 2024). The narrative of 'the other' in the dominant culture and the different influences at play make diversity by origin more than only 'a population with residents of different origins'. In this light, diversity emerges as a multifaceted reality, characterized and influenced by various layers and perspectives.

1.1.2 Challenged healthcare: The limitations of the "one-size-fits-all" care offer

The demographic trends discussed above enrich our society. However, they also bring several challenges to healthcare. Monitoring chronic conditions requires a different approach from the one traditionally employed. Moreover, it is crucial that healthcare does not exclude or discriminates individuals or groups and ensures equitable access to quality care. Equality in healthcare requires a tailored approach rather than a 'one-size-fits-all' approach, as the latter marginalizes individuals whose needs differ from the norm (Dell'aversana & Bruno, 2021). Failure to adequately address the increasing and changing care needs risks exacerbating the current inequalities and exclusion.

Inequalities in access, care quality, and outcomes.

The increasing diversity within healthcare settings has brought to light inequalities in care quality and access (Fjær, 2022; Hart & Mareno, 2014). Scientific research shows that patients from ethnic minority backgrounds often receive lower quality care (Chukwueke et al., 2022; Eneanya et al., 2022), less accurate diagnoses (Aylward et al., 2021; Nyante et al., 2022), and face significant inequalities in healthcare access and treatment (Luiking et al., 2019). Racial, ethnic, and socioeconomic disparities exist in all aspects of healthcare, e.g. diagnosis, treatment, and follow-up (Fjær, 2022; Nielsen et al., 2021; Osae et al., 2022). These inequalities became particularly apparent during the COVID-19 pandemic, which further marginalized already disadvantaged patient groups (Hasson et al., 2022; Stennett & Tsakos, 2022). Further, research has shown that patients from ethnic minority backgrounds report poorer self-assessed health and face a higher risk of serious conditions compared to the ethnic majority groups (Blom et al., 2016).

Barriers in accessing formal services include lack of information on formal services (Wangler & Jansky, 2021), and a lack of adapted services for persons with a migration background (Herat-Gunaratne et al., 2020; Sagbakken et al., 2018). Patients and informal carers face specific challenges, such as receiving less information and fewer referrals from professional care providers (Wangler & Jansky, 2021; Zemouri et al., 2024). This results in less interaction with and knowledge of these services (Duran-Kiraç et al., 2023; Mukadam et al., 2011; Nielsen et al., 2021). Additionally, the absence of ethnic-cultural-tailored healthcare organizations further exacerbates this issue, although such services could serve as gateways to broader formal care (Carlsson, 2023).

When accessing professional care services, patients and informal carers encounter barriers related to care quality, communication, and cultural sensitivity (Blix & Munkejord, 2022; Duran-Kiraç et al., 2022). There is often a mismatch between the expected quality of care and the actual care delivered, due to various factors, including language and communication barriers, lack of experience among care providers, and insufficient culturally sensitive practices (Blix & Munkejord, 2022; Duran-Kiraç et al., 2022; Stenberg & Hjelm, 2023). Moreover, discrimination and racist behaviour from healthcare providers can lead to distrust and negative experiences (Alpers, 2018; Zemouri et al., 2024).

The need to accommodate for patients from diverse backgrounds

Increased diversity within the population presents various challenges to healthcare. Firstly, there are challenges related to competences of healthcare providers. Healthcare providers must adapt their practices and attitude to accommodate patients from diverse cultural, ethnic, linguistic, and religious backgrounds (Nair & Adetayo, 2019; Wickramage et al., 2018). This adaptation includes addressing language barriers, respecting cultural beliefs and practices, and ensuring equitable access to care for all individuals, regardless of their background (Scheppers et al., 2006). Moreover, healthcare providers often hold stereotypical views about patients from diverse backgrounds, without realizing that this attitude can harm the trust relationship between them and their patients, affecting the quality of care ((Berdai Chaouni et al., 2020; Carlsson & Pijpers, 2020).

Secondly, there are challenges for healthcare organizations and the management of these organizations. If individual healthcare providers need to develop cultural competence and provide quality care to a diverse target group, then it is the responsibility of healthcare organizations to facilitate this. It requires cooperation from all levels in an organization to counter problems such as discrimination and exclusion. Research has shown that resistance and hesitation at this level is one of the main obstacles to providing culturally sensitive care (Dell’aversana & Bruno, 2021). Thirdly, also challenges at the healthcare system level must be considered. Time constraints and austerity measures increase the workload for healthcare providers. These circumstances, together with shortages in staff make it more challenging for healthcare providers to provide personalized care (Scheppers et al., 2006; Smith et al., 2000).

A frequently used approach in healthcare systems is the supply-oriented approach that revolves around the concept of 'the average patient', often failing to adequately address the diverse needs of individuals who fall outside this norm (Ellis et al., 2022; Karnati et al., 2020). Healthcare organizations prefer standardized and routine practices and services, tailored to fit the perceived average patient, thereby overlooking the unique requirements of marginalized patients (Ellis et al., 2022; Karnati et al., 2020). This rigid approach results in systemic exclusion of those who deviate from the established norms, among others individuals with diverse cultural backgrounds and varying healthcare needs (Nair & Adetayo, 2019). Consequently, a gap is created between the care and services provided and the actual needs of these underserved groups, leading to inequalities in care (Nielsen et al., 2019; Wickramage et al., 2018). Moreover, changes in the position of the patient, particularly in the deinstitutionalisation of care, challenge traditional care models centred around hospitals and healthcare providers. Healthcare systems must evolve towards a more integrated model to provide holistic care that addresses both the physical, mental, and social needs of patients. This evolution requires collaboration among different healthcare disciplines and community support services to ensure patients receive well-coordinated and effective care tailored to their individual needs (Casstelli et al., 2023).

Implementing new organizational models, like integrated care, requires multi-stakeholder action and integrated policies to address social, organisational, and financial barriers (Casstelli et al., 2023). In Belgium and in the region of Flanders, major changes are not happening, partly due to complex governance models. This is reflected in underutilization and underfinancing of prevention, fragmentation of care, the lack of a clear quality policy and poor cost-effectiveness of care (Vandeurzen & Steyaert, 2022). To conclude, it can be stated that the changing profile of the patient has brought new challenges and needs in healthcare. An increasingly older population and the increase in age-related conditions have led to more complex care needs. Additionally, a more diverse population have brought more diverse care needs. Changes in the healthcare system have led to a higher burden on informal carers. These evolutions have highlighted inequalities in healthcare, from access to care to diagnosis, treatment, and follow-up. The healthcare system is reaching its limits and cannot meet the evolving needs of patients. Consequently, the healthcare sector must seek new solutions, recognizing that the current system must adapt to these changing needs. Culturally sensitive care is suggested as an answer to meet these inequalities.

1.2 Culturally sensitive care as the solution?

Culturally sensitive care can be proposed as a solution to address challenges and inequalities in healthcare, aiming to improve among others health outcomes (Ellis et al., 2022). By developing cultural competences of healthcare providers, healthcare organisations aim to improve health related outcomes for diverse populations, e.g. patient satisfaction, adherence to treatment plans, or overall health outcomes (Sagar, 2012). However, while the aim of culturally sensitive care is promising, its implementation is challenged (Markey et al., 2018). The following section will describe culturally sensitive care from a theoretical perspective. Secondly, it explores the main research gaps in this area, including how culturally sensitive care is perceived by healthcare providers, as well as how professional care is experienced by informal carers with a migration background, and how the education of healthcare providers addresses culturally sensitive care.

1.2.1 What is culturally sensitive care?

Culturally sensitive care is an approach used when patients and healthcare provider from different ethnic and cultural backgrounds interact, seeking to build a better quality care relationship (Uzun & Sevinç, 2015; Young & Guo, 2020). This relationship is influenced by the cultural characteristics of both the patient and the healthcare provider. By accepting and overcoming cultural differences, a customized concept of care emerges: care that responds to the patient's questions and needs, regardless of their culture, religion, or origin. Although the concept of ‘culturally competent care’ is widely used in international scientific literature (Burchum, 2002; Markey et al., 2018; Papadopoulos & Lees, 2002), it is not commonly used in daily care practice in Flanders and Brussels, where ‘culturally sensitive care’ is preferred. The scientific literature shows that the term culturally sensitive care is also used in other European countries (Burchum, 2002; Shen, 2015; Sturm et al., 2017; Uzun & Sevinç, 2015). Both strands of literature are included in this PhD, and as the terms represent the same concept, they can be and will be used interchangeably.

Various models exist for providing culturally competent care, along with multiple definitions of cultural competence. Shen (2015) differentiates between theoretical models, which study cultural competence as a process involving a series of steps to achieve it (e.g., Campinha-Bacote Josepha, 1999; Cross et al., 1989; Sagar, 2012), and methodological models, which focus on the methods healthcare professionals can use to achieve cultural competence and provide culturally competent care (e.g., Davidhizar et al., 1998; Leininger, 1993; Sagar, 2012).

Campinha-Bacote, a leading author on the topic, follows the theoretical model and defines cultural competence as

> *"The ongoing process in which the healthcare professional continuously strives to achieve the ability to effectively work within the cultural context of the client (individual, family, community). This process involves the integration of cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire"* (Campinha-Bacote, 2002, p.181).

Leininger, who provided one of the first methodological models, defines cultural competence *as*

> *"The explicit use of culturally-based care and health knowledge that is used in sensitive, creative, and meaningful ways to fit the general lifeways and needs of individuals or groups for beneficial and meaningful health and well-being or to face illness, disabilities, or death"* (Leininger, 2002, p.117).

Even though different definitions and theoretical models exist, specific attributes are repeatedly cited when describing cultural competence within the various models, including these six attributes of cultural competence: cultural awareness, cultural knowledge, cultural sensitivity, cultural skill, cultural proficiency, and dynamicity (Sharifi et al., 2019). Cultural awareness helps healthcare providers to assess their own biases and assumptions and forms the basis for respecting the beliefs of others. Cultural knowledge forms the basis of the knowledge on which healthcare providers can rely in contact with other cultures. Cultural sensitivity is an attitude that recognizes, respects and values cultural diversity, whereby the healthcare provider looks at the patient with an open and respectful attitude. Cultural skill is the ability to provide care and communicate with people from other cultures. Cultural proficiency, related to the attribute cultural understanding, involves learning and sharing new cultural knowledge and skills through research and education, demonstrating a commitment to change. Dynamicity, related to the attribute cultural encounters, implies that the healthcare provider is continually becoming culturally competent by frequently interacting with diverse patients (Sharifi et al., 2019; Shen, 2015). In these models and theories, cultural competence is described as a type of additional competence that healthcare providers can develop. It is important to note that this assumes a general basic attitude that is common to all healthcare providers. This includes a respectful and empathetic attitude, with positive and kind personality characteristics (Jirwe M et al., 2006; Sharifi et al., 2019). Following this theoretical overview of culturally sensitive care, some knowledge gaps can be identified.

1.2.2 Research gaps

The gaps are explored from three perspectives: the perspective of the healthcare provider, the perspective of the informal carer, and the educational perspective.

How do healthcare providers experience culturally sensitive care?

Culturally sensitive care is expected to enhance patient satisfaction and improve health outcomes (Eneanya et al., 2022; Nair & Adetayo, 2019). Healthcare professionals must understand and consider how patients experience the world and reflect on their own biases and prejudices toward different cultural groups (Cai et al., 2017; Turner, 2005). Research among nurses confirms that knowledge, skills, and attitudes are important attributes for cultural competence (Hart & Mareno, 2014; Markey et al., 2018). However, cultural awareness and cultural sensitivity are mentioned less often in research among healthcare professionals. This may confirm a more ethnocentric lens of healthcare professionals toward cultural competence, as suggested in several previous studies (Almutairi et al., 2017; Seeleman C et al., 2009; Sumpter & Carthon, 2011). Healthcare providers must be aware of their own biases and preconceptions, critically reflecting on how these preconceptions influence patient interactions (Berdai Chaouni, 2021; Smallheer & Richard, 2024). Moreover, research shows that healthcare professionals feel insecure and have hesitations concerning the concept of culturally sensitive care, which may lead to changes in attitude when providing care for ethnic-diverse patients

(Markey et al., 2018; Roberts et al., 2007; Suurmond et al., 2010). Finally, language barriers, and stereotypical attitudes towards patients with a migration background hinder effective care provision (Berdai Chaouni et al., 2020; Carlsson & Pijpers, 2020; Scheppers et al., 2006).

Implementing culturally sensitive care faces various challenges. In addition to the individual barriers in perception discussed above, barriers towards implementation can also be identified across individual, interpersonal, organizational, and systemic levels (Eleri Jones et al., 2017; Scheppers et al., 2006; Suurmond et al., 2016). Healthcare providers experience barriers to implementing culturally sensitive care, such as limited linguistic proficiency and ineffective communication skills (Scheppers et al., 2006; Suurmond et al., 2016). The uncertainty and hesitation mentioned above is not only found at the individual healthcare provider, but is also described at the management level of healthcare organizations. Organizational resistance can form an obstacle to the implementation of culturally sensitive care in the organization (Dell'aversana & Bruno, 2021). Finally, there are also obstacles to implementing culturally sensitive care in the healthcare system. Resource constraints and heavy workloads can hinder the integration of culturally sensitive care in practice (Scheppers et al., 2006). Further research is necessary on how healthcare providers perceive culturally sensitive care and how this is implemented in practice. Not only the perspective of the individual healthcare provider must be taken into account. The perspective of the healthcare organization and the healthcare system must also be studied. Moreover, it is also important not only to map the barriers, but also to look at possible facilitators for the implementation of culturally sensitive care.

How do informal carers with a migration background experience professional care?

Taking into account that culturally sensitive care is suggested as a solution to various issues in healthcare, it is important to also explore how the patient and informal caregiver experience this culturally sensitive care. Recent research shows that the way in which healthcare professionals interpret culturally sensitive care does not always correspond with the way patients experience culturally competent and sensitive care, as research shows that the needs of patients and their informal carers remain unanswered and are unmet (Ospina-Caicedo et al., 2022; Tee et al., 2022; White et al., 2019). Informal carers with a migration background face challenges in accessing and using formal healthcare services. Research shows that informal carers with a migration background experience barriers in access to care. This may be due to a lack of information, too little knowledge about the provision and a lack of an appropriate healthcare offering (Parveen et al., 2018; Sagbakken et al., 2018; Wangler & Jansky, 2021). Moreover, obstacles to the use of care can be mentioned, e.g. when the quality of care often does not meet expectations of the informal carer, when there are language and communication barriers or the informal carers experience culturally insensitive care (Blix & Munkejord, 2022; Duran-Kiraç et al., 2022; Herat-Gunaratne et al., 2020). These obstacles and barriers suggest that the intended culturally sensitive care from the perspective of formal care provision - from the idea of 'good practice' - is experienced in a different way by informal carers. These findings indicate that it is necessary to further study informal cares' experiences with professional care, to see how informal carers with a migration background experience the professional care provided.

How does education of healthcare providers addresses culturally sensitive care?

The sections above discuss obstacles and barriers to implementing and putting into practice culturally sensitive care. In order to overcome these challenges, it is necessary to study how the topic of culturally sensitive care is implanted in education and training programs of future healthcare providers (Bell, 2023). Research shows that current training courses on cultural competences mainly focus on cultural aspects of 'the other cultures' and mainly focus on the transfer of knowledge (e.g., on religious traditions) and/or practical skills (e.g. communication skills) (Markey et al., 2018). Research however have shown that transfer of knowledge does not help in improving culturally sensitive actions of healthcare professionals, on the contrary it even leads to more stereotypical thinking (Berdai Chaouni et al., 2020). To achieve a behavioural change in practice, rather more self-awareness is needed (Eneanya et al., 2022). Health inequalities seem often not discussed in training on culturally sensitive care, and if mentioned, these discourses often lack an in-depth analysis of how whiteness and racism are contributing factors to these health inequalities (Ochs, 2023). Current training methods are inadequate for fostering culturally sensitive care practices (Almutairi et al., 2017; Tosun et al., 2021). These programs typically emphasize cultural knowledge transfer and practical skills acquisition (Long, 2014; Tosun et al., 2021). However, this approach often fails to promote self-awareness and can reinforce stereotypes, leading to misinterpretations and miscommunications (Berdai Chaouni, 2021; Markey et al., 2018). Practical skills training often focuses on stereotypical habits and traditions, further culturizing certain groups (Almutairi et al., 2017). In addition, while the content of culturally competent care training is debated in nursing literature, evidence-based insights on how students are and should be taught is lacking. Preliminary knowledge is most often based on the intuitive feeling and daily experience of teachers (Suurmond et al., 2021).

These findings necessitate further research on how cultural awareness and cultural sensitivity can be increased among students, with the aim to provide culturally sensitive care in the professional care practice. Considering this background and these findings and the three gaps in the current research, the following research gaps can be identified. It remains unclear:

1. The perception and implementation in practice of culturally sensitive care by healthcare providers
    - How do healthcare providers perceive and implement culturally sensitive care in practice?
    - What specific barriers and facilitators do they encounter, on the individual level, from their care organisations and from the healthcare system?
2. The experiences of professional care of informal carers with a migration background
    - How do informal carers with a migration background experience the professional care provided to their older relative?
3. The educational strategy to increase cultural awareness in nursing students
    - What are the most effective educational strategies for increasing self-awareness and critical reflection among future healthcare providers, and how can these strategies be implemented in training programs?

1.3 Outline of the dissertation

In the third section of this introduction, the research questions are presented, and an overview is given of the different chapters of this dissertation.

1.3.1 Research questions.

Three research gaps can be identified in the field of culturally sensitive care, which translate into the following research questions:

1) how do healthcare providers define, perceive and deliver culturally sensitive care?

Considering the information shared in the previous sections, it is necessary to study the challenges faced by healthcare providers when providing care to patients from diverse ethnic and cultural backgrounds. Further, it is necessary to explore the barriers and facilitators that healthcare providers encounter in delivering culturally sensitive care. In exploring these barriers and facilitators, different levels need to be considered: the individual and interpersonal levels of the healthcare professional, the level of management and organization, and the healthcare system.

2) how do informal carers of patients with a migration background experience the professional care they receive?

From the perspective of person-centred care, it is essential to include the voices of patients and informal carers in studying evolutions and changes in healthcare. Informal carers, being closest to the patient, play a crucial role in the overall care provision. However, it remains unclear how informal carers with a migration background experience the professional care provided. Therefore, it is necessary to explore how informal carers perceive the professional care given to older persons with a migration background.

3) how can future healthcare providers be trained in becoming culturally competent and sensitive healthcare providers?

It is necessary to design, implement, and evaluate an evidence-based training program to enhance the cultural competence and sensitivity of future healthcare professionals, with the aim to increase their awareness to provide culturally sensitive care. After designing, developing, and implementing, the training needs to be evaluated, and a strategy for implementation in the training needs to be developed.

Figure 1 gives a schematic overview of the research questions (RQ) that form the base of the studies in this dissertation.

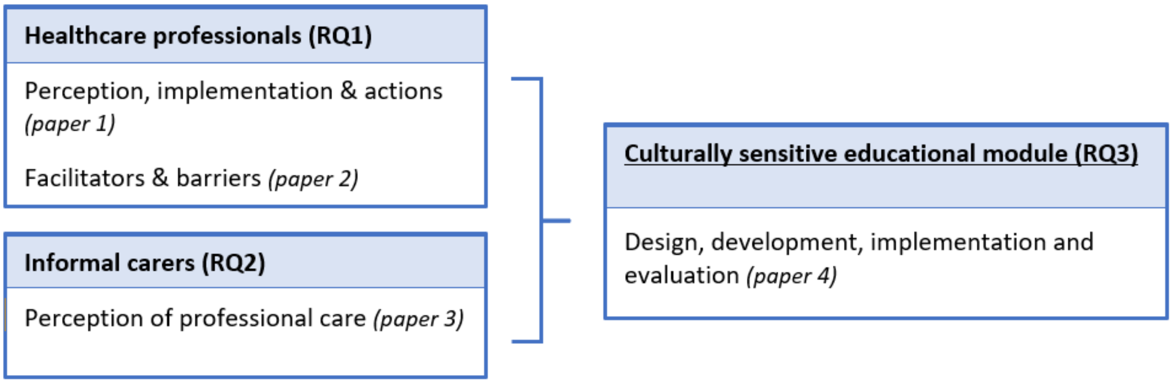

Figure 1: overview of the research questions

To summarise, this dissertation will study how culturally sensitive care is perceived and implemented in practice by healthcare providers and how it is seen from the perspective of the informal carer with a migration background. This evidence will be used to develop, implement, and evaluate an educational module for future healthcare providers.

1.3.2 Overview of the dissertation

This dissertation is divided into seven chapters.

Chapter 1 presents a general introduction to the dissertation. To outline the rationale behind the dissertation, an overview of the literature is given. This includes demographic and societal trends in current society, a description of how care for this changing population is provided and what barriers and research gaps exist. This chapter concludes with the research questions and outline of the dissertation.

Chapter 2 shows a comprehensive overview of the methodological approach utilized across the studies. This encompasses the research paradigm, an overview of the data used in this dissertation, and a statement regarding the researcher's positionality.

Chapter 3 identifies the definitions, perceptions, and practices of healthcare providers on culturally sensitive care. Data was derived from six focus groups (n = 34) and four in-depth interviews with six categories of healthcare providers. (paper 1)

Chapter 4 looks at the barriers and facilitators in providing care for patients with a migration background, from the perspective of the healthcare provider. Various levels in the healthcare system are addressed. Data was derived from six focus groups (n = 37) and 12 individual interviews with a multidisciplinary sample: doctors, nurses, social workers, and occupational therapists. Nursing and medical students were also included. (paper 2)

Chapter 5 presents the experiences with professional care as perceived by informal carers of older persons with a migration background and dementia. Seventeen informal carers from Italian and Turkish backgrounds were interviewed. Composite vignettes were utilized to present the results. (paper 3)

Chapter 6 presents the results of the development, implementation, and evaluation of an educational module, with the aim to increase cultural awareness in nursing students. This paper describes 1) the content of the module, led by the Johari Window model and the needs and insights from nursing students and healthcare providers, 2) the implementation, and 3) subsequent evaluation by 34 participants. (paper 4)

Chapter 7 presents a general discussion of this dissertation. The main findings of the different studies are discussed, as well as methodological reflections and limitations of the dissertation. Implications for policy and practice are presented.

Table 1 provides an overview of the studies included in this dissertation. In addition to the overarching research aim, each study outlines specific research questions. As Chapters 2 to 5 were initially written as independent manuscripts, submitted to international scientific journals, there might be some repetition. However, they are also structured to be understandable when read separately.

Table 1 Overview of studies included in this dissertation.

	Research Question	**Research Method**	**Data**	**Publication Status**
Chapter 3. Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals	1) What is the definition and perception of health care professionals of the concept of culturally sensitive care? 2) How is culturally sensitive care delivered by health care professionals in their daily practice?	Qualitative study using thematic content analysis	Six focus groups (n = 34) and four in-depth interviews were conducted with six categories of health care professionals	Published in Journal of Transcultural Nursing
Chapter 4. Barriers and facilitators in providing care for patients with a migration background	Which facilitators and barriers do healthcare professionals experience in providing care for patients with a migration background?	Qualitative study using thematic content analysis	Six focus groups (n = 37) and 12 individual interviews were conducted with a multidisciplinary sample: doctors, nurses, social workers, and occupational therapists, nursing and medical students	Published in Journal of Clinical Nursing
Chapter 5. Bridging the gaps: narratives of informal carers of older migrants with dementia on professional care	What are the experiences of informal carers with professional care, provided to an older person with migration background with dementia?	Inductive data analysis was employed using the Qualitative Analysis Guide of Leuven (QUAGOL), inspired by the constant comparative method of the Grounded Theory Approach. Composite vignettes were utilized to present the results.	17 individual interviews were conducted with informal carers from Italian and Turkish backgrounds.	Submitted to Ageing and Society
Chapter 6. Increasing Cultural Awareness in Nursing Students: Module Development, Implementation, and Evaluation	The aim of this study is to generate evidence on how the self-awareness of future healthcare professionals can be increased, by designing, developing and implementing an educational module, aiming at increasing cultural awareness in nursing student, and by consequently evaluating the intervention.	This paper describes 1) the content of the educational module, led by the Johari Window model and the needs and insights from nursing students and healthcare providers, 2) the implementation in a program for nursing students, and 3) subsequent evaluation.	Evaluation of the module among 34 participants.	Submitted to Journal of Professional Nursing

References

Almutairi, A. F., Adlan, A. A., & Nasim, M. (2017). Perceptions of the critical cultural competence of registered nurses in Canada. *BMC Nursing*, *16*, 1-9. https://doi.org/10.1186/s12912-017-0242-2

Alpers, L.-M. (2018). Distrust and patients in intercultural healthcare: A qualitative interview study. *Nursing Ethics*, *25*(3), 313-323. https://doi.org/10.1177/0969733016652449

Ang, S., Ho, E. L.-E., & Yeoh, B. S. A. (2022). Migration and new racism beyond colour and the “West”: Co-ethnicity, intersectionality and postcoloniality. *Ethnic and Racial Studies*, *45*(4), 585-594. https://doi.org/10.1080/01419870.2021.1925321

Arias-Casais, N., López-Fidalgo, J., Garralda, E., Pons, J. J., Rhee, J. Y., Lukas, R., de Lima, L., & Centeno, C. (2020). Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years. *Palliative Medicine*, *34*(8), 1044-1056. https://doi.org/10.1177/0269216320931341

Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder. *Journal of Developmental and Behavioral Pediatrics*, *42*(8), 682-689. https://doi.org/10.1097/DBP.0000000000000996

Bagger, S., Maindal, H. T., Nielsen, K. K., Vrå, A. G., & Aagaard-Hansen, J. (2021). Perceptions of risk and motivation for healthy living among immigrants from non-western countries with prior gestational diabetes mellitus living in Denmark. *Health Psychology and Behavioral Medicine*, *9*(1), 761-777. https://doi.org/10.1080/21642850.2021.1969235

Barbosa, F., Voss, G., & Delerue Matos, A. (2020). Health impact of providing informal care in Portugal. *BMC Geriatrics*, *20*(1), 440. https://doi.org/10.1186/s12877-020-01841-z

Belgisch Staatsblad. (2024, februari 24). *Wet tot wijziging van de wet van 22 augustus 2002 betreffende de rechten van de patiënt en tot wijziging van bepalingen inzake rechten van de patiënt in andere wetten inzake gezondheid*. https://www.ejustice.just.fgov.be/cgi/article_body.pl?language=nl&pub_date=2024-02-23&caller=summary&numac=2024001224

Bell, B. (2023). *The mobilization of anti-racism here is like squeezing a square peg through a round hole: A critical qualitative inquiry into anti-racism in settler-colonial Canadian nursing education*.

Bennet, L., Udumyan, R., Östgren, C. J., Rolandsson, O., Jansson, S. P. O., & Wändell, P. (2021). Mortality in first- and second-generation immigrants to Sweden diagnosed with type 2 diabetes: A 10 year nationwide cohort study. *Diabetologia*, *64*(1), 95-108. https://doi.org/10.1007/s00125-020-05279-1

Berdai Chaouni, S. (2021). *Grasping Fading Memories of a Motherland: Capturing Dynamic Care Realities of Older Labor Migrants with Dementia*. [PhD Thesis].

Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*, *101*(103413), 1-9. https://doi.org/10.1016/j.ijnurstu.2019.103413

Berkers, E., Cloïn, M., & Pop, I. (2021). Informal help in a local setting: The Dutch Social Support Act in practice. *Health Policy*, *125*(1), 47-53. https://doi.org/10.1016/j.healthpol.2020.09.007

Birukou, A., Blanzieri, E., Giorgini, P., & Giunchiglia, F. (2013). A Formal Definition of Culture. In K. Sycara, M. Gelfand, & A. Abbe (Red.), *Models for Intercultural Collaboration and Negotiation* (pp. 1-26). Springer Netherlands. https://doi.org/10.1007/978-94-007-5574-1_1

Blix, B., & Munkejord, M.-C. (2022). Indigenous Sami Family Caregivers' Experiences With Accessing and Collaborating With Municipal Health and Care Services. *Global Qualitative Nursing Research*, *9*. https://doi.org/10.1177/23333936221123333

Blom, N., Huijts, T., & Kraaykamp, G. (2016). Ethnic health inequalities in Europe. The moderating and amplifying role of healthcare system characteristics. *Social Science & Medicine*, *158*, 43-51. https://doi.org/10.1016/j.socscimed.2016.04.014

Bom, J., & Stöckel, J. (2021). Is the grass greener on the other side? The health impact of providing informal care in the UK and the Netherlands. *Social Science & Medicine*, *269*, 113562. https://doi.org/10.1016/j.socscimed.2020.113562

Botrugno, C. (2021). Information technologies in healthcare: Enhancing or dehumanising doctor–patient interaction? *Health*, *25*(4), 475-493. https://doi.org/10.1177/1363459319891213

Burchum, J. L. R. (2002). Cultural competence: An evolutionary perspective. *Nursing Forum*, *37*(4), Article 4.

Burzyńska, J., Bartosiewicz, A., & Januszewicz, P. (2023). Dr. Google: Physicians—The Web—Patients Triangle: Digital Skills and Attitudes towards e-Health Solutions among Physicians in South Eastern Poland—A Cross-Sectional Study in a Pre-COVID-19 Era. *International Journal of Environmental Research and Public Health*, *20*(2), Article 2. https://doi.org/10.3390/ijerph20020978

Cai, D., Kunaviktikul, W., Klunklin, A., Sripusanapan, A., & Avant, P. K. (2017). Identifying the essential components of cultural competence in a Chinese nursing context: A qualitative study. *Nursing & Health Sciences*, *19*(2), Article 2. https://doi.org/10.1111/nhs.12308

Campinha-Bacote, J. (2002). The Process of Cultural Competence in the Delivery of Healthcare Services: A Model of Care. *Journal of Transcultural Nursing*, *13*(3), Article 3. https://doi.org/10.1177/10459602013003003

Campinha-Bacote Josepha. (1999). *A Model and Instrument for Addressing Cultural Competence in Health Care*. 203-207.

Carlsson, H. (2023). Migrants' pathways to aged care: The role of local relationships of care in facilitating access for super-diverse older populations. *Ageing & Society*, *43*(7), 1502-1529. https://doi.org/10.1017/S0144686X21001240

Carlsson, H., & Pijpers, R. (2020). Working towards health equity for ethnic minority elders: Spanning the boundaries of neighbourhood governance. *Journal of Health Organization and Management*, *35*(2), 212-228. https://doi.org/10.1108/JHOM-08-2020-0325

Casstelli, M., Erskine, J., Hunter, D., & Hungin, A. (2023). The Forgotten Dimension of Integrated Care: Barriers to Implementing Integrated Clinical Care in English NHS Hospitals. *Health Economics Policy and Law*, *18*, 321.

Castellana, F., Lampignano, L., Bortone, I., Zupo, R., Lozupone, M., Griseta, C., Daniele, A., De Pergola, G., Giannelli, G., Sardone, R., & Panza, F. (2021). Physical Frailty, Multimorbidity, and All-Cause Mortality in an Older Population From Southern Italy: Results from the Salus in Apulia Study. *Journal of the American Medical Directors Association*, *22*(3), 598-605. https://doi.org/10.1016/j.jamda.2020.12.026

Charkaoui, N. (2019). *Racisme*. Epo. https://www.epo.be/nl/boeken/9789462671614

Chukwueke, U. N., Hervey-Jumper, S., & Porter, A. (2022). Disparities and Inequities Among Patients with Central Nervous System Tumor. *Hematology/Oncology Clinics*, *36*(1), e1-e8. https://doi.org/10.1016/j.hoc.2021.10.002

Cross, T. L., And Others, & Georgetown Univ. Child Development Center, W., DC. CASSP Technical Assistance Center. (1989). *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* (CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Rd., N.W., Washington, DC 20007 ($8.50).).

Culberson, J. W., Kopel, J., Sehar, U., & Reddy, P. H. (2023). Urgent needs of caregiving in ageing populations with Alzheimer's disease and other chronic conditions: Support our loved ones. *Ageing Research Reviews*, *90*, 102001. https://doi.org/10.1016/j.arr.2023.102001

Darcis, C., Schoenaers, F., & Thunus, S. (2022). The Belgian mental health reform: When a combination of soft instruments hampers structural change. *Governance*, *35*(2), 437-456. https://doi.org/10.1111/gove.12608

Davidhizar, R., Bechtel, G., & Giger, J. N. (1998). A Model to Enhance Culturally Competent Care. *Hospital Topics*, *76*(2), Article 2. https://doi.org/10.1080/00185869809596495

Dell'aversana, G., & Bruno, A. (2021). Supporting Cultural Competence: Practices of Managers and Line Workers in a Health Service. *TPM: Testing, Psychometrics, Methodology in Applied Psychology*, *28*(1), 65-81. https://doi.org/10.4473/TPM28.1.5

D'herde, J., Gruijthuijsen, W., Vanneste, D., Draulans, V., & Heynen, H. (2021). "I Could Not Manage This Long-Term, Absolutely Not." Aging in Place, Informal Care, COVID-19, and the Neighborhood in Flanders (Belgium). *International Journal of Environmental Research and Public Health*, *18*(12), Article 12. https://doi.org/10.3390/ijerph18126482

Donder, L. D., Kint, O., Dikmans, B., & Degraeve, L. (2023). Zorgzame buurten: Toegankelijke zorg in de buurt. *AGORA Magazine*, *39*(3), Article 3. https://doi.org/10.21825/agora.90371

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., van Hout, H., & Broese van Groenou, M. I. (2022). Accessibility of health care experienced by persons with dementia from ethnic minority groups and formal and informal caregivers: A scoping review of European literature. *Dementia (London, England)*, *21*(2), 677-700. https://doi.org/10.1177/14713012211055307

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., van Hout, H., & Broese van Groenou, M. I. (2023). Informal caregiver and nurse perceptions of access to culturally appropriate health care for ethnic minority persons with dementia: A qualitative study. *Journal of Advanced Nursing (John Wiley & Sons, Inc.)*, *79*(8), 3002-3014. https://doi.org/10.1111/jan.15687

Eleri Jones, Samantha R. Lattof, & Ernestina Coast. (2017). Interventions to provide culturally-appropriate maternity care services: Factors affecting implementation. *BMC Pregnancy and Childbirth*, *17*(1), 1-10. https://doi.org/10.1186/s12884-017-1449-7

Ellis, D. M., Draheim, A. A., & Anderson, P. L. (2022). Culturally adapted digital mental health interventions for ethnic/racial minorities: A systematic review and meta-analysis. *Journal* *of Consulting and Clinical Psychology*, *90*(10), 717-733. https://doi.org/10.1037/ccp0000759

Eneanya, N. D., Boulware, L. E., Tsai, J., Bruce, M. A., Ford, C. L., Harris, C., Morales, L. S., Ryan, M. J., Reese, P. P., Thorpe, R. J., Morse, M., Walker, V., Arogundade, F. A., Lopes, A. A., & Norris, K. C. (2022). Health inequities and the inappropriate use of race in nephrology. *Nature Reviews Nephrology*, *18*(2), Article 2. https://doi.org/10.1038/s41581-021-00501-8

Fjær, E. L. (2022). *Inequalities in Health Care Utilization in Europe* [Doctoral thesis, NTNU]. https://ntnuopen.ntnu.no/ntnu-xmlui/handle/11250/2987785

FOD Justitie. (2024). *Dubbele nationaliteit | Federale overheidsdienst justitie*. https://www.justitie.belgium.be/nl/themas_en_dossiers/personen_en_gezinnen/nationaliteit/dubbele_nationaliteit

Hart, P. L., & Mareno, N. (2014). Cultural challenges and barriers through the voices of nurses. *Journal of Clinical Nursing*, *23*(15/16), Article 15/16. https://doi.org/10.1111/jocn.12500

Hasson, R., Sallis, J. F., Coleman, N., Kaushal, N., Nocera, V. G., & Keith, N. (2022). COVID-19: Implications for Physical Activity, Health Disparities, and Health Equity. *American Journal of Lifestyle Medicine*, *16*(4), 420-433. https://doi.org/10.1177/15598276211029222

Herat-Gunaratne, R., Cooper, C., Mukadam, N., Rapaport, P., Leverton, M., Higgs, P., Samus, Q., & Burton, A. (2020). “In the Bengali Vocabulary, There Is No Such Word as Care Home”: Caring Experiences of UK Bangladeshi and Indian Family Carers of People Living With Dementia at Home. *The Gerontologist*, *60*(2), 331-339. https://doi.org/10.1093/geront/gnz120

Jaul, E., & Barron, J. (2017). Age-Related Diseases and Clinical and Public Health Implications for the 85 Years Old and Over Population. *Frontiers in Public Health*, *5*. https://doi.org/10.3389/fpubh.2017.00335

Jirwe M, Gerrish K, & Emami A. (2006). The theoretical framework of cultural competence. *Journal of Multicultural Nursing & Health (JMCNH)*, *12*(3), Article 3.

Karaman, N., & Christian, M. (2020). “My Hijab Is Like My Skin Color”: Muslim Women Students, Racialization, and Intersectionality. *Sociology of Race and Ethnicity*, *6*(4), 517-532. https://doi.org/10.1177/2332649220903740

Karnati, S. A., Wee, A., Shirke, M. M., & Harky, A. (2020). Racial disparities and cardiovascular disease: One size fits all approach? *Journal of Cardiac Surgery*, *35*(12), 3530-3538. https://doi.org/10.1111/jocs.15047

King, R. (2019). Diverse, Fragile and Fragmented: The New Map of European Migration. *Central and Eastern European Migration Review*, *8*(1), 9-32.

Kuosmanen, L., Hupli, M., Ahtiluoto, S., & Haavisto, E. (2021). Patient participation in shared decision-making in palliative care – an integrative review. *Journal of Clinical Nursing*, *30*(23-24), 3415-3428. https://doi.org/10.1111/jocn.15866

Leininger, M. (1993). Towards Conceptualization of Transcultural Health Care Systems: Concepts and a Model. *Journal of Transcultural Nursing*, *4*(2), Article 2. https://doi.org/10.1177/104365969300400206

Leininger, M. (2002). Culture Care Theory: A Major Contribution to Advance Transcultural Nursing Knowledge and Practices. *Journal of Transcultural Nursing*, *13*(3), Article 3.

Li, Z., Zhang, Z., Ren, Y., Wang, Y., Fang, J., Yue, H., Ma, S., & Guan, F. (2021). Aging and age-related diseases: From mechanisms to therapeutic strategies. *Biogerontology*, *22*(2), 165-187. https://doi.org/10.1007/s10522-021-09910-5

Long, T. (2014). Influence of international service-learning on nursing student self-efficacy toward cultural competence. *The Journal of Nursing Education*, *53*(8), 474-478. https://doi.org/10.3928/01484834-20140725-02

Luiking, M., Heckemann, B., Ali, P., Doorn, C., Ghosh, S., Kydd, A., Watson, R., & Patel, H. (2019). Migrants' Healthcare Experience: A Meta-Ethnography Review of the Literature. *Journal of Nursing Scholarship*, *51*(1), Article 1. https://doi.org/10.1111/jnu.12442

Markey, K., Tilki, M., & Taylor, G. (2018). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *27*(1-2), Article 1-2. https://doi.org/10.1111/jocn.13926

Marsella, A. J. (2009). Diversity in a Global Era: The context and consequences of differences. *Counselling Psychology Quarterly*. https://doi.org/10.1080/09515070902781535

Mårtensson, L., Lytsy, P., Westerling, R., & Wångdahl, J. (2020). Experiences and needs concerning health related information for newly arrived refugees in Sweden. *BMC Public Health*, *20*(1), 1044. https://doi.org/10.1186/s12889-020-09163-w

Méroc, E., Moreau, N., Lebacq, T., Dujeu, M., Pedroni, C., Godin, I., & Castetbon, K. (2019). Immigration and adolescent health: The case of a multicultural population. *Public Health*, *175*, 120-128. https://doi.org/10.1016/j.puhe.2019.07.001

Mitchell, E., & Walker, R. (2020). Global ageing: Successes, challenges and opportunities. *British Journal of Hospital Medicine*, *81*(2), 1-9. https://doi.org/10.12968/hmed.2019.0377

Molina-Mula, J., & Gallo-Estrada, J. (2020). Impact of Nurse-Patient Relationship on Quality of Care and Patient Autonomy in Decision-Making. *International Journal of Environmental Research and Public Health*, *17*(3), Article 3. https://doi.org/10.3390/ijerph17030835

Moore, M., & Wesselbaum, D. (2023). Climatic factors as drivers of migration: A review. *Environment, Development and Sustainability*, *25*(4), 2955-2975. https://doi.org/10.1007/s10668-022-02191-z

Moosavi, L. (2015). The Racialization of Muslim Converts in Britain and Their Experiences of Islamophobia. *Critical Sociology*, *41*(1), 41-56. https://doi.org/10.1177/0896920513504601

Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, *23*(7), 1070-1077. https://doi.org/10.1017/S1041610211000214

Mukherjee, S. K., Pandey, V., Singh, A., & Jha, A. (2022). Emergence of social media as a collaborative and knowledge-sharing tool of health information during pandemic. In *Digitalisation and Organisation Design*. Routledge.

Nair, L., & Adetayo, O. A. (2019). Cultural Competence and Ethnic Diversity in Healthcare. *Plastic And Reconstructive Surgery. Global Open*, *7*(5), Article 5. https://doi.org/10.1097/GOX.0000000000002219

Neuberger, J., & Tallis, R. (1999). We do need a new word for patients? *British Medical Journal*, *318*(7200), 1756-1756.

Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2019). Barriers to post-diagnostic care and support in minority ethnic communities: A survey of Danish primary care dementia coordinators. *Dementia (London, England)*, 1471301219853945-1471301219853945. https://doi.org/10.1177/1471301219853945

Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2021). Barriers in access to dementia care in minority ethnic groups in Denmark: A qualitative study. *Aging & Mental Health*, *25*(8), 1424-1432. https://doi.org/10.1080/13607863.2020.1787336

Nyante, S. J., Abraham, L., Aiello Bowles, E. J., Lee, C. I., Kerlikowske, K., Miglioretti, D. L., Sprague, B. L., Henderson, L. M., & Breast Cancer Surveillance Consortium. (2022). Diagnostic Mammography Performance across Racial and Ethnic Groups in a National Network of Community-Based Breast Imaging Facilities. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, *31*(7), 1324-1333. https://doi.org/10.1158/1055-9965.EPI-21-1379

Ochs, J. H. (2023). Addressing health disparities by addressing structural racism and implicit bias in nursing education. *Nurse Education Today*, *121*, 105670. https://doi.org/10.1016/j.nedt.2022.105670

Osae, S. P., Chastain, D. B., & Young, H. N. (2022). Pharmacists role in addressing health disparities—Part 1: Social determinants of health and their intersectionality with medication use, health care utilization, and health outcomes. *JACCP: JOURNAL OF THE AMERICAN COLLEGE OF CLINICAL PHARMACY*, *5*(5), 533-540. https://doi.org/10.1002/jac5.1565

Ospina-Caicedo, A., Castro Franco, E., Torres Andrade, M. V., Caicedo, J. L., Tombé Morales, M. C., & Peláez-Ballestas, I. (2022). Culturally sensitive care of Misak Indigenous patients with rheumatoid arthritis in Colombia. *Rural and Remote Health*, *22*(2), 6698. https://doi.org/10.22605/RRH6698

Papadopoulos, I., & Lees, S. (2002). Developing culturally competent researchers. *Journal of Advanced Nursing*, *37*(3), Article 3. https://doi.org/10.1046/j.1365-2648.2002.02092.x

Parlevliet, J. L., Uysal-Bozkir, Ö., Goudsmit, M., van Campen, J. P., Kok, R. M., Ter Riet, G., Schmand, B., & de Rooij, S. E. (2016). Prevalence of mild cognitive impairment and dementia in older non-western immigrants in the Netherlands: A cross-sectional study. *International Journal of Geriatric Psychiatry*, *31*(9), Article 9. https://doi.org/10.1002/gps.4417

Parveen, S., Blakey, H., & Oyebode, J. R. (2018). Evaluation of a carers' information programme culturally adapted for South Asian families. *International Journal of Geriatric Psychiatry*, *33*(2), e199-e204. https://doi.org/10.1002/gps.4768

Plugmann, J., & Plugmann, P. (2021). Digitalization from the Patients' Perspective. In P. Glauner, P. Plugmann, & G. Lerzynski (Red.), *Digitalization in Healthcare: Implementing Innovation and Artificial Intelligence* (pp. 43-50). Springer International Publishing. https://doi.org/10.1007/978-3-030-65896-0_4

Ratcliffe, P. (2004). *Race Ethnicity and Difference: Imagining the Inclusive Society*. McGraw-Hill Education (UK).

Robards, F., Kang, M., Luscombe, G., Hawke, C., Sanci, L., Steinbeck, K., Zwi, K., Towns, S., & Usherwood, T. (2020). Intersectionality: Social Marginalisation and Self-Reported Health Status in Young People. *International Journal of Environmental Research and Public Health*, *17*(21), Article 21. https://doi.org/10.3390/ijerph17218104

Roberts, J. H., Sanders, T., & Wass, V. (2007). Students' perceptions of race, ethnicity and culture at two UK medical schools: A qualitative study. *Medical Education*, *0*(0), Article 0. https://doi.org/10.1111/j.1365-2923.2007.02902.x

Roccas, S. (2005). Religion and Value Systems. *Journal of Social Issues*, *61*(4), 747-759. https://doi.org/10.1111/j.1540-4560.2005.00430.x

Sagar, P. (2012). *Transcultural Nursing Theory and Models: Application in Nursing Education, Practice, and Administration (Springer, 2012)*.

Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC Health Services Research*, *18*(1), 910. https://doi.org/10.1186/s12913-018-3720-7

Scheppers, E., van Dongen, E., Dekker, J., Geertzen, J., & Dekker, J. (2006). Potential barriers to the use of health services among ethnic minorities: A review. *Family Practice*, *23*(3), 325-348. https://doi.org/10.1093/fampra/cmi113

Schneider, U., Sundström, G., Johannson, L., & Tortosa, M. A. (2015). Policies to support informal care. In *Long-Term Care Reforms in OECD Countries* (pp. 219-244). Policy Press. https://bristoluniversitypressdigital.com/edcollchap/book/9781447305064/ch010.xml

Scholten, P. (Red.). (2022). *Introduction to Migration Studies: An Interactive Guide to the Literatures on Migration and Diversity*. Springer International Publishing. https://doi.org/10.1007/978-3-030-92377-8

Seeleman C, Suurmond J, & Stronks K. (2009). Cultural competence: A conceptual framework for teaching and learning. *Medical Education*, *43*(3), Article 3. https://doi.org/10.1111/j.1365-2923.2008.03269.x

Sharifi, N., Adib-Hajbaghery, M., & Najafi, M. (2019). Cultural competence in nursing: A concept analysis. *International Journal of Nursing Studies*, *99*, 103386. https://doi.org/10.1016/j.ijnurstu.2019.103386

Shen, Z. (2015). Cultural Competence Models and Cultural Competence Assessment Instruments in Nursing: A Literature Review. *Journal of Transcultural Nursing*, *26*(3), Article 3.

Smallheer, B., & Richard, -Eaglin Angela. (2024). Implementation of Cultural Awareness and Cognitive Bias Training Within Graduate Nursing Programs. *Journal of Nursing Education*, *0*(0), 1-4. https://doi.org/10.3928/01484834-20240318-03

Smith, G. D., Chaturvedi, N., Harding, S., Nazroo, J., & Williams, R. (2000). Ethnic inequalities in health: A review of UK epidemiological evidence. *Critical Public Health*, *10*(4), 375-408. https://doi.org/10.1080/09581590010005331

Statbel. (2022, juni 16). *Diversiteit naar herkomst in België | Statbel*. https://statbel.fgov.be/nl/nieuws/diversiteit-naar-herkomst-belgie-0#:~:text=De%20diversiteit%20naar%20herkomst%20is,punt%20tussen%202002%20en%202012

Statbel. (2024, februari 13). *Bevolkingsvooruitzichten | Statbel*. https://statbel.fgov.be/nl/themas/bevolking/bevolkingsvooruitzichten

Statistiek Vlaanderen. (2023, juli 5). *Bevolking naar leeftijd en geslacht*. www.vlaanderen.be. https://www.vlaanderen.be/statistiek-vlaanderen/bevolking/bevolking-naar-leeftijd-en-geslacht

Stenberg, J., & Hjelm, K. (2023). Migrant informal caregiver perceptions and experiences of caring for a family member with dementia: A systematic review and thematic synthesis. *Journal of Clinical Nursing*, *32*(9-10), 2178-2192. https://doi.org/10.1111/jocn.16390

Stennett, M., & Tsakos, G. (2022). The impact of the COVID-19 pandemic on oral health inequalities and access to oral healthcare in England. *British Dental Journal*, *232*(2), Article 2. https://doi.org/10.1038/s41415-021-3718-0

Steyaert, J. (2014). *De meervoudigheid van vermaatschappelijking*. *105*, 11-16.

Sturm, G., Bonnet, S., Coussot, Y., Journot, K., & Raynaud, J.-P. (2017). Cultural Sensitive Care Provision in a Public Child and Adolescent Mental Health Centre: A Case Study from the Toulouse University Hospital Intercultural Consultation. *Culture, Medicine & Psychiatry*, *41*(4), Article 4. https://doi.org/10.1007/s11013-017-9538-7

Sumpter, D. F., & Carthon, J. M. B. (2011). Lost in Translation: Student Perceptions of Cultural Competence in Undergraduate and Graduate Nursing Curricula. *Journal of Professional Nursing*, *27*(1), Article 1. https://doi.org/10.1016/j.profnurs.2010.09.005

Suurmond, J., Lantinga, K., de Voogd, X., Oueslati, R., Boland, G., & van den Muijsenbergh, M. (2021). Twelve tips to teach culturally sensitive palliative care. *Medical Teacher*, *43*(7), 845-850. https://doi.org/10.1080/0142159X.2020.1832650

Suurmond, J., Rosenmöller, D. L., El Mesbahi, H., Lamkaddem, M., & Essink-Bot, M.-L. (2016). Barriers in access to home care services among ethnic minority and Dutch elderly—A qualitative study. *International Journal of Nursing Studies*, *54*, 23-35. https://doi.org/10.1016/j.ijnurstu.2015.02.014

Suurmond, J., Seeleman, C., Rupp, I., Goosen, S., & Stronks, K. (2010). Cultural competence among nurse practitioners working with asylum seekers. *Nurse Education Today*, *30*(8), Article 8. https://doi.org/10.1016/j.nedt.2010.03.006

Tee, S., Üzar-Özçetin, Y. S., & Trenoweth, S. (2022). Achieving culturally competent mental health care: A mixed-methods study drawing on the perspectives of UK nursing students. *Perspectives in Psychiatric Care*, *58*(4), 1267-1280. https://doi.org/10.1111/ppc.12926

Timonen, V., & Lolich, L. (2020). Dependency as Status: Older Adults' Presentations of Self as Recipients of Care. *Sage Open*, *10*(4), 2158244020963590. https://doi.org/10.1177/2158244020963590

Torres, S. (2019). *Ethnicity and Old Age—Expanding our Imagination*. Policy Press. https://policy.bristoluniversitypress.co.uk/ethnicity-and-old-age

Tosun, B., Yava, A., Dirgar, E., Şahin, E. B., Yılmaz, E. B., Papp, K., Tóthova, V., Hellerova, V., Prosen, M., Licen, S., Karnjus, I., Tamayo, M. D. B., Leyva-Moral, J. M., Claeys, A., & Tricas-Sauras, S. (2021). Addressing the effects of transcultural nursing education on nursing students' cultural competence: A systematic review. *Nurse Education in Practice*, *55*, 103171. https://doi.org/10.1016/j.nepr.2021.103171

Turner, L. (2005). Is cultural sensitivity sometimes insensitive? *Canadian Family Physician Medecin De Famille Canadien*, *51*, 478.

UN Migration. (2019). *The World Migration Report 2020*. https://worldmigrationreport.iom.int/wmr-2020-interactive/

UNESCO. (2001, november 2). *UNESCO Universal Declaration on Cultural Diversity—Legal Affairs*. https://www.unesco.org/en/legal-affairs/unesco-universal-declaration-cultural-diversity

Uzun, Ö., & Sevinç, S. (2015). The relationship between cultural sensitivity and perceived stress among nurses working with foreign patients. *Journal of Clinical Nursing*, *24*(23-24), Article 23-24. https://doi.org/10.1111/jocn.12982

Vandeurzen, J., & Steyaert, S. (2022). *Geïntegreerde zorg: Werken aan samenwerken* (1ste dr.). Lannoo Campus.

Vertovec, S. (2007). Super-diversity and its implications. *Ethnic and Racial Studies*, *30*(6), 1024-1054. https://doi.org/10.1080/01419870701599465

Volckaert, E., Schillebeeckx, E., & De Decker, P. (2021). Beyond nostalgia: Older people's perspectives on informal care in rural Flanders. *Journal of Rural Studies*, *87*, 444-454. https://doi.org/10.1016/j.jrurstud.2020.07.006

Wangler, J., & Jansky, M. (2021). Support, needs and expectations of family caregivers regarding general practitioners – results from an online survey. *BMC Family Practice*, *22*(1), 1-12. https://doi.org/10.1186/s12875-021-01381-4

White, J., Plompen, T., Tao, L., Micallef, E., & Haines, T. (2019). What is needed in culturally competent healthcare systems? A qualitative exploration of culturally diverse patients and professional interpreters in an Australian healthcare setting. *BMC Public Health*, *19*(1), 1096. https://doi.org/10.1186/s12889-019-7378-9

WHO, & Global Health Observatory. (2020). *Life expectancy and healthy life expectancy*. https://www.who.int/data/gho/data/themes/mortality-and-global-health-estimates/ghe-life-expectancy-and-healthy-life-expectancy

Wickramage, K., Vearey, J., Zwi, A. B., Robinson, C., & Knipper, M. (2018). Migration and health: A global public health research priority. *BMC Public Health*, *18*. https://doi.org/10.1186/s12889-018-5932-5

Wong, E., Mavondo, F., Horvat, L., McKinlay, L., & Fisher, J. (2022). Healthcare professionals' perspective on delivering personalised and holistic care: Using the Theoretical Domains Framework. *BMC Health Services Research*, *22*(1), 281. https://doi.org/10.1186/s12913-022-07630-1

Young, S., & Guo, K. L. (2020). Cultural Diversity Training: The Necessity of Cultural Competence for Health Care Providers and in Nursing Practice. *The Health Care Manager*, *39*(2), 100. https://doi.org/10.1097/HCM.0000000000000294

Zemouri, C., Kassi, A. N., Oñate, W. A. de, Çoban, G., & Kissi, A. (2024). Exploring discrimination and racism in healthcare: A qualitative phenomenology study of Dutch persons with migration backgrounds. *BMJ Open*, *14*(6), e082481. https://doi.org/10.1136/bmjopen-2023-082481

Chapter 2: Methodological approach

This chapter summarizes the methodology employed across the different studies within the dissertation. Section 1 describes the research paradigm and design. Section 2 describes the data used in the studies. Section 3 offers a statement regarding my researcher's positionality.

2.1 Research paradigm and design

The underlying approach for the studies is the interpretive approach. The focus lies on understanding human actions. With the approach of interpretivism the studies want to give understanding of how healthcare providers and informal carers interpret and understand care within the complex environment of healthcare (Alharahsheh & Pius, 2019; Guba & Lincoln, 1994). Based on the classification of Guba and Lincoln (1994), the research paradigm for the studies in this dissertation aligns with a constructivist approach. Constructivism begins with ontological relativism, from the idea that the world is a human construction, and that one objective reality does not exist. Constructivists posit multiple possible realities, implying that each person perceives reality uniquely, thereby creating their 'own' reality (Guba & Lincoln, 1994; Mortelmans, 2009; Ryan, 2018).

Applied to the studies in this dissertation, the focus is on understanding the perspectives of healthcare providers, informal carers, and nursing students. For healthcare providers, culturally sensitive care is examined from their own perspective, reflecting the construction of their individual reality. For informal carers, personal narratives are analysed to explore their construction of reality regarding professional care provision. When evaluating the educational module, the study starts from the reality of the nursing students that followed the module, capturing their construction of reality. The study on barriers and facilitators for healthcare providers explored their interpretation of reality within the structure of their working environment, acknowledging the complexities of the environment. This study includes the exploration of perceived barriers and facilitators at the individual, organizational, and systemic levels. The epistemological consequence of constructivism is the interconnectedness of the researcher and the research object. Thus, the constructivist researcher must be aware and acknowledge the link between themselves and their research object (Alharahsheh & Pius, 2019; Mortelmans, 2009; Ryan, 2018). Reflection between researchers and self-reflection were integral parts of every study in this dissertation.

From the interpretive tradition that is constructivism, various movements have emerged, all sharing the fundamental idea that reality is a social construction (Kinchelow & Mclaren, 2002; Mortelmans, 2009). Ideas of social constructionism and critical theory are also interwoven throughout the studies in this dissertation. In social constructivism, Berger and Luckmann argue that the social world is not constructed by individuals alone but is a collective social creation. Meaning is shared socially and passed on across generations (Berger & Luckmann, 2011). In addition, the historical realism of critical theory begins with the idea that a reality is only 'real' because it exists under the influence of social, political, cultural, economic, and ethnic factors into fixed structures that are be considered 'real'. Critical theory states that all thoughts are fundamentally shaped by power relations, which themselves are products of social and historical processes, with constant influences from the capitalist production and consumption mode. It emphasizes the privilege of certain groups and the oppression of others (Kinchelow & Mclaren, 2002; Mortelmans, 2009). These aspects are included in the studies, particularly in the analysis and discussion of the findings. For instance, for the concept of othering, the underlying influence of critical theory cannot be denied. Furthermore, it is important to note that the healthcare providers, informal carers, and students involved in the studies live and operate within society, thereby experiencing the influences of its social constructions.

Interpretivist research methods, often in a qualitative design, aim to capture the richness of human experience and involve interactive processes like interviews, focus groups or participatory action research. These methods prioritize engagement and collaboration, enabling participants to actively contribute to the construction of meaning (Blaikie & Priest, 2017; Rahi, 2017). Key characteristics of this design include asking research questions about complex themes or social processes, exploring and understanding people's living environments, and focusing on the daily realities of the participants. The design aims to achieve a holistic understanding of the context and remains flexible in its design, method, and analysis (Beck & Polit, 2014; Mortelmans, 2009). In line with this research paradigm, the studies in this dissertation use a qualitative research design to study the meaning of people’s lives within their real-world contexts, representing their perspectives and identifying contextual conditions. This approach allows the discovery of nuanced perceptions and the complexity of interpretations (Beck & Polit, 2014; Rahi, 2017). The qualitative research design used in these studies aims to understand the experiences and perceptions of healthcare providers and informal carers in the context of culturally sensitive care.

Specific to the design, development, and implementation of the educational module, it aligns with paradigms more related to an educational approach (Baker et al., 2019). The research paradigm for the design, development and implementation of the module is primarily transformative, incorporating key elements of the humanist research paradigm in education within the context of healthcare. It aims at social change and equity in healthcare through culturally competent education while also strengthening personal growth, by social justice issues, challenging power structures, and promoting equity. It is concerned with changing societal norms and empowering individuals through research and education. This paradigm is inherently action-oriented (Baker et al., 2019; McKivett & Paul, 2024).

Applied to the study, the educational module seeks empowerment and change through a training program designed to challenge biases and power dynamics in healthcare settings. It aims to enhance the cultural competence of future healthcare providers, which is essential for delivering quality care services to diverse populations. Additionally, the study focuses on personal growth and awareness of the student. It implements with a practical, action-oriented design that is characteristic of transformative research methodologies (Baker et al., 2021). By focusing on actionable steps and interventions, the study seeks to address societal issues and enhance transformative practices.

2.2 Description of the data used in this dissertation.

This section outlines the data used in the studies and provides a description of the Diverse Elderly Care project.

2.2.1 Data used in the studies

The dissertation is structured around three research questions (RQ). The first research question (RQ1) studies how healthcare providers define, perceive and deliver culturally sensitive care, and identifies facilitators and barriers for culturally sensitive care from the perspective of the healthcare provider. The second research question (RQ2) focuses on the experiences of informal carers, particularly those caring for older first-generation labour migrants with dementia. The third research question (RQ3) centres on the development, implementation, and evaluation of an educational module about culturally sensitive care for nursing students.

The study on how healthcare providers define, perceive and deliver culturally sensitive care.

Data collection and respondents: the first research question focused on gathering insights from healthcare providers regarding culturally sensitive care. Data collection involved in total eight focus group interviews (n = 46) and 15 individual in-depth interviews. Participants included general practitioners, nurses, midwives, paramedics and students from nursing, midwifery, and medicine programs. The selection process for respondents utilized consecutive sampling for focus groups and purposive sampling for individual interviews. Interviews were conducted face-to-face. All interactions followed the ethical and GDPR guidelines and were audio-recorded with informed consent.

Materials and analysis: An interview guide based on a literature review structured the discussions around definitions, practices, facilitators, and barriers to culturally sensitive care. The interviews were transcribed verbatim and supplemented with field notes. Thematic content analysis, using Burnard's model, facilitated the classification of data into relevant themes (Burnard et al., 2008). The qualitative data analysis software MAXQDA© supported coding and analysis, ensuring a thorough examination of the healthcare providers' perspectives.

Output: This study is used in Chapter 3 and 4.

The study on experiences with professional care as perceived by informal carers of older migrants with dementia

Data collection and respondents: The second research question explored the experiences of informal carers, focusing on culturally sensitive dementia care for older first-generation labour migrants in Brussels. Seventeen individual interviews were conducted with informal carers of Italian and Turkish backgrounds. The respondents, comprising 11 women and 6 men, were recruited through community networks using purposively sampling. Interviews were held in Dutch, French, or Turkish with interpreters, respecting participants' preferences.

Materials and analysis: Interviews were audio-recorded, transcribed verbatim, and accompanied by field notes. Inductive data analysis was employed using the Qualitative Analysis Guide of Leuven (QUAGOL), inspired by the constant comparative method of the Grounded Theory Approach (Dierckx de Casterlé et al., 2012). Composite vignettes were utilized to present the findings

Output: This study is used in Chapter 5.

The study on the development, implementation, and evaluation of an educational module for nursing students.

Data collection and respondents: The third research question focused on developing, implementing, and evaluating an educational module for nursing students. This involved developing, implementing, and evaluating a 4-hour intervention in a bachelor nursing program, using curriculum mapping, focus group interviews, and post-intervention surveys. The module was integrated into a course on specific patient needs, involving 34 second-year nursing students with diverse backgrounds.

Materials and analysis: The design of the module was based on the Johari Window conceptual framework, highlighting awareness in cultural competence. Data collection included thematic analysis of student survey responses. The coding tree, derived from survey questions, guided the analysis using MAXQDA© software, ensuring a comprehensive evaluation of the students' experiences and the effectiveness of the educational module.

Output: This study is used in Chapter 6.

2.2.2 The Diverse Elderly Care - project

In this chapter, it is necessary to situate the Diverse Elderly Care project, a practice-oriented scientific research project of Erasmushogeschool Brussels, with the financial support of the European Fund for Regional Development Brussels. The project spanned five years (2016-2021) and involved scientific partners, as well as partners from healthcare, welfare, and community organisations.

The research design primarily used a practice-oriented approach. The results were gathered in a unique setting, incorporating both longitudinal follow-up of the dementia trajectory and cross-sectional interviews with older persons, informal carers, and healthcare providers. Throughout the entire research process, all stakeholders were actively engaged. The study focused first-generation labour migrants with dementia from Moroccan, Turkish, or Italian origin living in Belgium, subsequently reaching out the older persons themselves, their informal carers and healthcare providers.

Data from this project was used in the studies discussed in this dissertation. More specifically, data from the interviews and focus groups with the healthcare providers from this project was used for the studies of research question 1, supplemented with data collected outside this project. Data from the interviews with informal carers of Turkish and Italian origin from this project were used for the study of research question 2. Since the results of research questions 1 and 2 form the basis for the development of the educational module in research question 3, the elaboration of this module is also related to this project.

The project led to an extensive pioneer study of the case of dementia in older persons with a migration background, studied over a longer period and from different perspectives. The results of the project were published in a book in Dutch and French, and several scientific papers and more popular publications resulted from this project (Berdai Chaouni et al., 2021; Berdai Chaouni & Claeys, 2022; Berdai-Chaouni & Claeys, 2021; Claeys et al., 2020, 2022).

2.3 Positionality statement of the researcher

I would like to begin by acknowledging that my personal background (being a white, female researcher), my educational background in nursing (Bachelor's) and gerontology (Master's), and my professional background has shaped me as a researcher. My positionality as a researcher, nurse, lecturer, and individual, all intertwined, shapes my commitment to explore perspectives on culturally sensitive care, aiming to promote more inclusive and equitable healthcare. Firstly, from my viewpoint as a healthcare provider, my objective is to deliver quality care to all patients, without exclusion. This commitment is rooted in a sense of professional honour. Secondly, as a researcher, I want to investigate and understand the challenges involved in implementing culturally sensitive care within practice. Lastly, from a personal standpoint, as someone who contributes to and relies on a social security system, I expect this system to serve everyone equitably, without exclusion. In my research, this positionality allows me to switch between different lenses, while remaining aware of the perspective each lens offers.

My position as a nurse and lecturer

With approximately 20 years of work experience, divided between healthcare and educational settings, I reflect on my journey. As a nurse, my perspective on care aligns with patient-centred care and the recognition of ethnic cultural diversity. Despite my broader experience in healthcare and welfare, my primary viewpoint often remains that of a nurse. I approach this research with a commitment to explore the perspectives of both healthcare providers and informal carers, acknowledging the importance of mutual understanding, respect, and sensitivity in this topic. From the perspective of informal carers, this work addresses the limitations of the healthcare system and healthcare providers regarding person-centred and quality care. I acknowledge and recognize the experiences of informal carers, while also seeing the struggling, tired, and overburdened healthcare providers. As a lecturer in nursing education, I understand the significance of education in enhancing cultural competence among future healthcare providers. Through my teaching experience, I am aware of the potential barriers to implementing culturally sensitive care practices and the importance of addressing these obstacles. My dual experience as a nurse and lecturer has given me insight into the challenges future healthcare providers may encounter due to ongoing changes and evolving needs in healthcare and society.

My position as a researcher

Research has been an integral part of my career, beginning when I worked as a nurse and meanwhile, I completed my Master’s in Gerontology. Following that, I taught in a nursing program (Bachelor's), where I taught courses related to care for older adults, care in an urban context, and evidence-based nursing. In addition to teaching, I have consistently volunteered for research projects, mainly focusing on care in an urban context and care for older adults. I was able to work part-time on a project titled "Diverse Elderly Care," which focused on dementia in older persons with a migration background. This work sparked my interest in culturally sensitive care, leading to my specialization in the topic. After meeting my PhD supervisor, Prof. Liesbeth De Donder, and her research group SARLab, I began a voluntary PhD trajectory. Research has become the lens through which I critically examine my field, whether I am teaching, working as a nurse, or fulfilling other roles. I collect data, analyse situations from multiple perspectives, and engage in insightful conversations. I perceive both self-reflectivity and team reflectivity within a diverse research group as essential for conducting research on this theme. Reflectivity in the research team involved exchanging perspectives, discussing results, sharing doubts, and always doing so in a safe environment.

My position as a person

My own life experiences, including providing informal care for my grandparents and being a mother of two children, have shaped my perspective on healthcare as a user of care services. These individual experiences have heightened my awareness of the complex dynamics in healthcare provision and the importance of person-centred quality care. On a personal level, I openly acknowledge my white western background, devoid of migration history, which encompasses themes like othering, racism, and discrimination. I recognize the privilege inherent in my positionality and strive to use it responsibly to advocate for inclusive healthcare practices. Developing self-awareness around the theme of racial discrimination and exclusion is a ongoing process for me. I am aware that this theme is influenced by historical contexts, is continually evolving, and encompasses diverse perspectives. As a result, discussing racial discrimination and exclusion from my positionality can feels like navigating a challenging path, accompanied by the fear of inadvertently causing harm. Nevertheless, I approach these issues pragmatically and take proactive steps to engage with them. My personal values of empathy and respect motivate my commitment to comprehending and addressing barriers to accessible quality care.

References

Alharahsheh, H., & Pius, A. (2019). *A Review of key paradigms: Positivism VS interpretivism*. *1*.

Baker, L., Wright, S., Mylopoulos, M., Kulasegaram, K., & Ng, S. (2019). Aligning and Applying the Paradigms and Practices of Education. *Academic Medicine*, *94*(7), 1060. https://doi.org/10.1097/ACM.0000000000002693

Beck, C. T., & Polit, D. F. (2014). *Essentials of nursing research. Appraising evidence for nursing practice* (Campus Jette - GEZ 613.2; 8e ed.). Wolters Kluwer.

Berdai Chaouni, S., & Claeys, A. (2022). *Démence chez les personnes agées d'issue d'immigration*. Garant / Maklu.

Berdai Chaouni, S., Claeys, A., van den Broeke, J., & De Donder, L. (2021). Doing research on the intersection of ethnicity and old age: Key insights from decolonial frameworks. *Journal of Aging Studies*, *56*. https://doi.org/10.1016/j.jaging.2020.100909

Berdai-Chaouni, S., & Claeys, A. (2021). *Dementie bij ouderen met een migratieachtergrond*. Maklu. https://www.maklugarant.eu/nl/products/details/dementie-bij-ouderen-met-een-migratieachtergrond-242409

Berger, P. L., & Luckmann, T. (2011). *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*. Open Road Media.

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal*, *204*(8), 429-432. https://doi.org/10.1038/sj.bdj.2008.292

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2020). Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals. *Journal of Transcultural Nursing*, 1043659620970625. https://doi.org/10.1177/1043659620970625

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & Donder, L. D. (2022). Barriers and facilitators in providing care for patients with a migration background. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.16491

Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, *49*(3), 360-371. https://doi.org/10.1016/j.ijnurstu.2011.09.012

Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In *Handbook of qualitative research* (pp. 105-117). Sage Publications, Inc.

Kinchelow, J., & Mclaren, P. (2002). Rethinking Critical Theory and Qualitative Research. In *Key Works in Critical Pedagogy* (Vols. 87–138). https://doi.org/10.1007/978-94-6091-397-6_23

Mortelmans, D. (2009). *Handboek kwalitatieve onderzoeksmethoden* (2de dr.). Acco. https://shop.acco.be/nl-be/items/9789463799072/Handboek-kwalitatieve-onderzoeksmethoden

Ryan, G. (2018). Introduction to positivism, interpretivism and critical theory. *Nurse Researcher*, *25*(4), Article 4.

Chapter 3: Culturally sensitive care: definitions, perceptions and practices of healthcare professionals

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Abstract

Introduction

An increasing number of patients from diverse backgrounds in Western cities is drawing attention to the concept of culturally-sensitive care. Research highlights that patients from ethnic minority groups often receive lower quality of care. The purpose of this study was to deepen knowledge and understanding of culturally-sensitive care by exploring 1) the definition and perception of healthcare professionals of the concept of culturally-sensitive care, and 2) how culturally-sensitive care is delivered by healthcare professionals in daily practice.

Methods

The design of the study was a qualitative methodology using six focus groups (n = 34) and four in-depth interviews with six categories of respondents in Belgium: nursing students, qualified nurses, midwife students, qualified midwives, medical students and qualified physicians. Thematic content analysis was used to analyse the data.

Results

The results indicate that healthcare professionals and students define and perceive the concept of culturally-sensitive care narrowly: there is a strong focus on practical issues and on Muslim patients. Moreover, healthcare professionals are more likely to handle from their own frame of reference and find it challenging to show empathy with patients with a different frame of reference. Othering (micro-racism by defining ‘the other’) is a specific example of this.

Discussion

Increasing cultural awareness and sensitivity within the health setting are essential to going beyond the current narrow definitions and practices of culturally-sensitive care. Increasing awareness that ‘othering’ creates barriers when caring for patients and family carers of ethnic minorities is an important challenge.

Keywords

cultural diversity, cultural competence, culturally-sensitive care, healthcare professional, focus groups

3.1 Introduction

Today's approximately 1,208,542 inhabitants of Brussels, the capital of Belgium, comprise a very ethnically and culturally diverse population. According to the World Migration Reports, up to 182 different nationalities live in the capital region of Brussels, making it the most cosmopolitan city of Europe and second in the world (Statbel, 2015, UN Migration, 2019). Between 1946 and 1970, the Belgian state received labour migrants from Italy, Greece, Spain, Morocco and Turkey. After the 70s, the migration population kept growing for a variety of reasons (Lafleur et al., 2018). According to recent data, in the capital region of Brussels, 71.4% of the inhabitants have migrant roots (Agency Internal Affairs, 2018). Other Western cities are also being confronted with large numbers of different nationalities and ethnic backgrounds.

This diversity also translates into an increasing number of patients from diverse cultural, ethnic and linguistic backgrounds. Scientific research highlights that patients from ethnic minority groups often receive lower quality of care and less accurate diagnosis (Hart & Mareno, 2014; Taylor, 2005). In addition, it appears that there are profound inequities and disparities towards these groups when they need healthcare (Brondolo et al., 2009; Hart & Mareno, 2014; Luiking et al., 2019). Culturally-sensitive care is expected to enhance patient satisfaction as well as to improve health outcomes (Green-Hernandez et al., 2004; Kim-Godwin et al., 2001). This paper aims to provide insight into how healthcare professionals define and perceive culturally-sensitive care and how they (try to) deliver culturally-sensitive care in daily practice.

Culturally-sensitive care is an approach that is used when patient and healthcare professional – from different ethnic-cultural backgrounds – are in interaction with each other to search for a connection in order to build a (better quality) care relationship (Uzun & Sevinç, 2015). This care relationship is affected by the cultural characteristics of both the patient and the healthcare professional. By accepting and overcoming these cultural differences, a customized concept of care starts: care that responds to the questions and needs of the patient, regardless of their culture, religion or origin. Although the concept of 'culturally-competent care' is widely used in the international scientific literature (Burchum, 2002; Markey et al., 2018; Papadopoulos & Lees, 2002), this concept is not used in daily care practice in Flanders and/or Brussels, where the concept of 'culturally-sensitive care' is favoured. The scientific literature shows that the concept of culturally-sensitive care is also used is other European countries – for example, in the Netherlands and France (Burchum, 2002; Shen, 2015; Sturm et al., 2017; Uzun & Sevinç, 2015). For the purposes of this paper, both strands of literature are included, and both terms appear to represent the same concept and are used interchangeably.

There are various models for providing culturally-competent care, along with a number of definitions of cultural competence. Shen (2015) differentiates between theoretical models in which cultural competence is studied from a process perspective, as a series of steps to be taken to achieve cultural competence (e.g. Campinha-Bacote, 1999; Cross et al., 1989; Sagar, 2011), and methodological models that focus on the methods that a healthcare professional can use in order to achieve cultural competence and to provide culturally-competent care (e.g. Davidhizar et al., 1998; Leininger, 1993; Sagar, 2011). While the theoretical models focus more on 'competence' (with different attributes or domains such as awareness, knowledge, sensitivity, and skills), the methodological models seem to emphasize 'cultural', encompassing aspects of religion, ethnicity, healing beliefs and practices (Shen, 2015). This division has its effects when defining 'cultural competence'.

> Campinha-Bacote, a leading author on the topic, follows the theoretical model and defines cultural competence as: “*the ongoing process in which the healthcare professional continuously strives to achieve the ability to effectively work within the cultural context of the client (individual, family, community). This process involves the integration of cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire*” (Campinha-Bacote, 2002, p.181). Leininger, who provided one of the first methodological models, defines cultural competence as: “*the explicit use of culturally-based care and health knowledge that is used in sensitive, creative, and meaningful ways to fit the general lifeways and needs of individuals or groups for beneficial and meaningful health and well-being or to face illness, disabilities, or death*” (Leininger, 2002, p.117).

Even though different definitions and theoretical models exist, specific attributes are repeatedly cited when describing cultural competence within the different models. Shen (2015) analysed 15 cultural competence models and assessment instruments and found that four attributes were present in 13 of the 15 cultural competence models or assessment instruments: namely, awareness, knowledge, skills and sensitivity. Cultural knowledge and cultural skills are often mentioned in scientific research as attributes necessary to gaining cultural competence (Burchum, 2002; Campinha-Bacote, 2002; Shen, 2015).

When investigating the perspective of the healthcare professional in practice, research among nurses confirms that knowledge, skills and attitudes are important attributes for cultural competence (Seeleman et al., 2009; Shepherd et al., 2019; Suurmond et al., 2010). It is important for healthcare professionals to understand and take into account how a patient experiences the world, and that carers must reflect on their own biases and prejudices towards different cultural groups (Cai et al., 2017; Turner, 2005). Cultural awareness and cultural sensitivity are mentioned less often in literature among healthcare professionals. On the one hand, this may confirm a more ethnocentric point of view of healthcare professionals towards cultural competence, alluded to in several previous studies(Almutairi et al., 2017; Hopkins et al., 2020; Seeleman C et al., 2009; Sumpter & Carthon, 2011). On the other hand, research also shows that healthcare professionals have queries concerning this concept. This may translate into feeling insecure when providing culturally-sensitive care or simply when talking about ethnicity, race and cultural diversity (Jirwe et al., 2006; Markey et al., 2018; Roberts et al., 2007; Suurmond et al., 2010).

In response to the aforementioned research, the purpose of this study is to deepen knowledge and understanding of culturally-sensitive care by exploring: 1) the definition and perception of healthcare professionals of the concept of culturally-sensitive care, and 2) how culturally-sensitive care is delivered by healthcare professionals in their daily practice.

3.2 Methods

This qualitative study is part of the larger Diverse Elderly Care research project, which examines culturally-sensitive dementia care for older migrants in Brussels, from the perspectives of elders, family carers and healthcare professionals. This paper focuses on the perspective of the healthcare professional. Ethics approval was granted by the Ethics committee of the university hospital in Brussels (CE 2016-105).

A qualitative research method was used because it is most suitable when exploring definitions, perspectives and practices in healthcare, as is the case in this study (Beck & Polit, 2014; Bernard & Bernard, 2000). The COREQ checklist was used to report the method of our study (Tong et al., 2007).

3.2.1 Research team and reflexivity

The first and second authors conducted the focus groups and interviews. Both are researchers and have experience in the field of healthcare, culturally-sensitive care and qualitative research. All authors have experience in qualitative research and content analysis, and all are teaching in a healthcare training programme. Both interviewers reflected comprehensively on their role and bias in this study. The relationship with the participants varies from 'known in a professional context' to 'unknown'. Before each focus group session or interview, the researchers were presented, and the project purpose, the process of the focus group session, and the terms on ethics and privacy were explained.

3.2.2 Study design

Focus group interviews were conducted with healthcare professionals (nurses, midwives) and students (nursing, midwife and medicine), who were selected by using consecutive sampling. The participants were invited face-to-face during a seminar or during class. For certain participants (general practitioners), individual interviews were organised because it was difficult to accommodate the focus group sessions for this group of professionals. General practitioners were selected by purposive sampling for the same reason. They were invited by e-mail and telephone by the first or second author. They were recruited from a network of healthcare providers in Brussels. All respondents participated in focus group interviews or individual interviews on a voluntary basis. Having experience in healthcare (as a job or from an internship) in a diverse city (e.g. Brussels) was an inclusion criterium for all participants. Data collection took place between November 2017 and September 2018. The two-hour focus group sessions were scheduled at a convenient time for the participants. The sessions were audio taped after obtaining verbal informed consent from the participants at the beginning of each group session. The focus group interviews took place in a meeting room at a university college in Brussels and were conducted in Dutch. The individual interviews took place at the GPs' individual offices and were conducted in Dutch. A total of six focus group interviews (n = 34) and four in-depth interviews were conducted. In total, 23 students participated in four focus group interviews; and 11 healthcare professionals participated in two focus groups. Table 1 provides an overview of basic demographic information of the study participants. Data saturation was obtained. All focus group interviews and 1 individual interview were conducted by the first author. The second author assisted in conducting focus group 5 and performed three individual interviews. Participants were reassured that, although the sessions were being audiotaped, anonymity was guaranteed. No names were traceable in the transcriptions, and numbers are used as substitutes for names. All interviews were audiotaped and transcribed verbatim by an official transcription office. An interview guide, based on the literature review, was used to structure the interviews. The literature review focused on cultural competence models and definitions. The interview started with the question: "What is good (quality of) care?" This more general topic was used as an ice breaker to stimulate discussion among the participants. Thereafter, 4 main topics were used to shed light onto the topic examined:

1) How do you define and perceive culturally-sensitive care (in theory and in practice)?
2) How do you (try to) provide culturally-sensitive care in practice?

3) What are facilitators for, and barriers to, culturally-sensitive care?
4) What is the role of the patient and the healthcare organisation in culturally-sensitive care?

In order to not influence the perception of the participants regarding the topic, no *a priori* definition or description of culturally-sensitive care was provided. After each focus group session and interview, a debriefing report was made, including observational notes and comments about the process of the session.

3.2.3 Analysis

Thematic content analysis was used to analyse the data, and our analysis was coded and elaborated according to Burnard's model (Beck & Polit, 2014; Bengtsson, 2016; Burnard et al., 2008; Burnard, 1991). The central aim of content analysis is to classify the data into more relevant and manageable parts or themes, which makes this methodological framework suitable for exploring definitions, perceptions and practices (Graneheim & Lundman, 2004; Weber, 1990).

The data were coded by one coder, using the qualitative data analysis software MAXQDA©. The coding tree was built on the main themes of the interview guide, including the 4 attributes, as presented earlier (cultural awareness, knowledge, skills, sensitivity). After initial coding, the data were explored in-depth. After a first analysis round, the authors discussed the coding of the data. A second analysis round led to 5 major emerging themes, which were again discussed by the research team. A third round of analysis led to the findings presented in this paper.

3.3 Results

The main emerging findings for the two first research topics are reviewed. Results are presented as a unit for the different types of participants (students, professionals) and the different disciplines (nurse, midwife, doctor) together, because the topic is explored from the perspective of the healthcare professional in general. This research does not aim to compare the perspectives of the different disciplines.

3.3.1 A narrow definition and perception of culturally-sensitive care

Although the respondents agreed with each other that all patients should be treated equally and with respect, the respondents often had a narrow definition of culturally-sensitive care. First, culturally-sensitive care meant caring for 'the other'. The other is different – and that is at the centre of the challenge of culturally-sensitive care. In defining 'the other', the participants mentioned certain groups of immigrants very frequently, whereas other groups were not mentioned at all. When talking about culturally-sensitive care, native Belgian respondents very often defined the other 'culture' as 'religion', and, more specifically, as 'Islamic religion'. In general, there was a strong focus on Muslim patients and on patients with roots in the Northern Africa and Middle East countries, as the following quotes illustrate:

> *"in Arab countries, it is expected that the doctor takes the decision without involving the patient, and in our culture the doctor sometimes asks: 'what do you think of that?'" (medical student, FG4)*
>
> *"in Muslim countries, the relationship with the doctor is different. … I cannot exactly say which countries, but there certainly are countries like that." (nurse, FG5)*

Conversely, respondents with roots in South-East Europe or North Africa did not make this link with religion, and they saw 'other cultures' as different ethnic groups: for example, patients from Eastern Europe or from Central Africa. None of the native Belgian respondents mentioned patients from Eastern or Southern Europe as an example of patients with a different culture.

Second, the respondents gave a list of practical actions as examples of how culturally-sensitive care is implemented in their daily care provision. The practical actions were based on the stereotypes that the respondents associate with immigrants from other cultures, and with Muslim immigrants, in particular: for example, providing halal-food or providing a translator. A preference for the healthcare professional's gender, specific food requests and translation support were most often mentioned as examples.

The respondents did not always give examples from their own experience about these practical actions. Often these examples were based on stories from other healthcare professionals or from mentors to the student-respondents. As an example, there was only one lived experience with a professional translator (see citation below), and the other experiences were 'heard from colleagues' or were shared experiences with non-professional translators. The latter experiences were called difficult, unnecessary or practically impossible. Almost all examples were about problems, negative experiences, or an extra effort that the respondents gave in order to meet the needs of the patient, as the following quote shows:

> *INTERVIEWER: "You say: 'I think that it is (more difficult) because of the cultural difference.' Why do you say that?"*
>
> *RESPONDENT: "Because I hear from other colleagues that that is the case." (physician, INT2)*

Third, as a solution to the fact they have experienced culturally-sensitive care to be difficult, the respondents stressed the fact that they needed more (cultural) knowledge in order to feel able to provide culturally-sensitive care. They said that they needed to know more about other cultures, but they did not differentiate between culture and religion. The examples they gave showed that they wanted more specific information about Islam, as this quote illustrates:

"Education programmes could be about what (cultural) differences are, and where they come from, in order to better understand each other. For example, why Muslims don't eat pork?" (nurse, FG5)

Some respondents mentioned that it is also important to have an open and inquiring attitude towards patients, and that years of working experience can also increase knowledge about different cultures.

3.3.2 Providing culturally-sensitive care is difficult

Our study participants perceived culturally-sensitive care to be difficult. They considered it a challenge. First, the respondents wanted to gain knowledge in order to feel prepared in situations with patients that are perceived as 'other' or different. They perceived culturally-sensitive care as a situation out of their comfort zone and were eager to learn more about the characteristics of different ethnic-cultural groups. They expected a third party (the universities, their employers) to provide this knowledge, and they were unlikely to take actions themselves to broaden their knowledge. They felt insecure about their own (cultural) knowledge.

> *“If you have some idea about how to act, it seems to go a bit easier. If you have a broader knowledge – for example, of communication skills – then it is easier to act and to handle – for example, knowing that you don’t extend your hand to women from Saudi-Arabia.” (medical student, FG4)*

Secondly, the respondents were anxious about being regarded as racist, and so they hesitated to communicate and act in a spontaneous way. The reluctance to work in a spontaneous way led to feelings of exhaustion, as this next quote illustrates:

> *“It is very exhausting to constantly have to think about how to communicate with someone.” (nurse, FG5)*

The perception that culturally-sensitive care is difficult can be caused by the idea that the respondents had about culturally-sensitive care: namely, that patients expect you to do something different. So, this supposed expectation was caused by ‘the other’. And because the other is perceived to be different, the respondents expected such patients to have other needs. As a consequence of these other needs, they presumed they were expected to act differently and exert more effort, as this quote shows:

> *“For example, closing the door while having a conversation. I do that with every mother, but especially with mothers with a head scarf.” (midwife, FG6)*

The respondents did not like this feeling of uncertainty and tried to find ways to handle these feelings – by using certain assumptions, acting shy and low-profile, or, at times, by overacting.

> *“But getting to know a patient is never only based on questions and answers. You do that anyway based on appearance, behaviour, ... All those little things give you an image of that person, how he/she lives their life, ... I don’t think it is wrong to admit ... a woman wearing a head scarf, I have certain assumptions about that.” (medical student, FG4)*

> *“They come from God-knows-where, and with the Berber and all... I always have an extremely good connection with those people. I give them a hug, and those mothers aren’t embarrassed, they do their thing ... that’s no problem.” (nurse, FG5)*

The respondents think that broader knowledge and being more experienced as a healthcare professional was reassuring and provided the feeling of being more confident, mastering better communication, and providing better caring skills.

Third, the respondents referred to a lack of time as an additional factor enhancing the perception of culturally-sensitive care as being difficult. The respondents indicated that time is an important condition for providing good quality of care for every patient. In the current cost-savings climate, professionals have less time to do what is considered to be more work. As already mentioned, the respondents expected other needs, and acted differently or exerted more effort towards patients with a different cultural background. Too little time, too much work, and the idea that certain types of patients require even more time, lead to conflicting demands which are difficult for the healthcare professional to handle in daily practice.

> *“... there were frustrations with the physician, frustrations with the nurses, and there was no patience. ‘They don’t even understand us, so why do we have to keep investing time (in them)’, in this way...” (midwife, FG6)*

> *“During my last placement, I was on my way to the waiting room to get a patient. A nurse took my arm and said: ‘you don’t have to invest too much time in her, that black woman’*

> *and then she let go of my arm. I thought 'what just happened?', but I went to the patient and did what I was supposed to do. Afterwards, I was typing my report, and she (the nurse) came back to me and said, 'that was a typical black one, wasn't she?' Just because someone has a different skin colour doesn't mean that they don't deserve the time and effort I would also give to someone else. So, I was really shocked by that." (medical student, FG4)*

This last quote also shows a final difficulty mentioned by the respondents in regard to working with different ethnic-cultural groups, and that is the lack of competence to face racism towards patients. Several respondents reported that they felt unprepared and insecure about responding to racist comments by colleagues or (in the case of students) mentors.

3.3.3 Culturally-sensitive care is delivered to 'the other', starting from their own frame of reference

The respondents centralise themselves as the norm, and they start from this frame of reference to compare how alike or different patients are. The frame of reference is a construction of values, norms, knowledge, and experience. It is dynamic and individually set, but there are also important structural influencers from the society, such as educational and governmental systems. First, most of the respondents made it very clear that there was a difference between 'us' and 'them', and they keep seeing some people as 'the other', as this quote illustrates:

> *"We adapt often to other cultures, but they also have to respect us, and they also must be open towards us. Yes, it needs some interaction because it is not only us ..." (nurse, FG5)*

Similar statements were expressed during the entire discourse with the healthcare professionals. The next citations show that there is also an imbalance of power between 'us' and 'them', which needs to be considered:

> *"Look, that doesn't mean that there are people that receive less quality of care... Not at all. But they don't have to start acting difficult. They have to adapt (to our system), that is the rule." (nurse, FG5)*

Additionally, they use of words such as 'regular people' and 'normal people' to indicate people 'like us' shows that a distinction is being made between different types of people.

> *"In winter, when it snows, I automatically remove my shoes... then I don't ask, I also do that in normal people's houses." (nurse, FG5)*

Secondly, communication skills and asking genuinely open questions are often presented by the respondents as good practices for getting to know the patient and their habits. But even when the respondents asked their patients open and sincere questions, the othering continued, as this example shows:

> *"So, I ask them: 'How do they do that with you (meaning: with your kind of people)?" (nurse, FG5)*

This example demonstrates that the respondent saw the daughter and the patient as a part of a larger group, namely Muslims. And in that perception all Muslims have similar habits and traditions. It is important to note that the respondents were not aware of this othering during their discourse.

Third, this ‘othering’ mentality became noticeable in how behaviour or relationships were described by the participants. The participants shared situations and examples simply from their own point of view and from their own frame of reference.

The respondents usually showed little awareness of, or sensitivity towards, the diversity of frames of reference among people, as the next quote illustrates:

> *“For us, it is more difficult in home care, because you are with those people at home and most of those people say: ‘you have to take off your shoes and wear slippers.’ No, I am not going to do that, because if I have to do that with everybody, then I lose half an hour by just taking my shoes off and putting them back on again. Then there is an arrangement made with that family and we have a meeting, and we say: ‘sorry, but we are not going to start doing that’.” (nurse, FG5)*

There were several similar examples given, where this pattern was common: we (healthcare professionals) respect you (the patient) and we will listen to you, but eventually it will be ‘our’ way and within ‘our’ boundaries. There is a fear in the respondents’ statements about adapting too much to the needs of the patients. Clear communication was perceived as saying what they find possible or not, and in which circumstances.

For the respondents with a migration background, it was easier to empathize towards the patient’s frame of reference. They found it easier to consider that there are different ways of thinking. White Belgian respondents who showed some awareness towards people with another frame of reference confirmed that their point of view on the world played a role in how they provided care. That point of view was influenced by how they were raised and educated, by travelling, or by years of experience as a healthcare professional in a diverse setting. They displayed awareness that everyone has assumptions, but that it is important to be aware of that, as the following quote shows:

> *“Working experience and experience with patients is the only way to increase your (self)awareness. Educational packages seem to be an easy and fast solution, but the only solution is extensive patient contact.” (nurse, FG5)*

During the interviews and focus groups, the respondents showed their good intentions and presented themselves as truly committed to their patients. They were not aware of this ‘othering’ neither that it could be a potential barrier towards the patient.

3.4 Discussion

In the present study, healthcare professionals and students were interviewed regarding their perspectives on culturally-sensitive care. First of all, the findings suggest that the definition, perception and practices of culturally-sensitive care by healthcare professionals and future professionals are often narrow and focused on daily care practice. When examining and looking further into the definition of culturally-sensitive care by the healthcare professionals, it is clear that there is a specific focus on the Islamic religion and/or Arabic culture. In previous research conducted by Torres, it is explained how the ‘elder immigrants’ group is created as a social construct and is categorised as a ‘homogeneous problematic group with special needs’. A similar pattern applies to the perception of Muslim patients (Torres, 2006). This can be a result of the current framing in society in Western countries, where Islam is often presented in media, social media and policy in a negative and stereotypical way. Fadil (2019) confirms this narrow point of view, on the societal level, where ‘culture’ equals ‘migrants’, and that ‘migrants’ equal ‘Muslims’ (Fadil, 2019).

Conversely, the findings show that the perception of Muslim healthcare professionals with a migration background is different. Here a different type of perception of culturally-sensitive care is identified, which is based more on ethnicity and less on religion. Moreover, healthcare providers with a migration background have a wider range of populations and nationalities in mind when defining culturally-sensitive care.

Second, findings show that healthcare providers perceive culturally-sensitive care as difficult – they feel insecure, and they search for solutions in the domain of (cultural) knowledge to comfort themselves and to feel less insecure. This is also confirmed in other research, which additionally states that cultural knowledge does not improve the quality of care for the patient (Berdai Chaouni et al., 2020; Resnicow et al., 1999).

Another important remark is that ‘one type of immigrant’ does not exist. Migrants are very diverse in the areas of origin, age, current socio-economic status, culture, motive for migration, socio-economic status before migration, educational level and literacy, among others. For all these attributes, Torres (2006) states that ‘immigrantness’ holds certain characteristics such as foreign, culturally different, less developed, more traditional and less modern. This ‘immigrantness’ or otherness creates feelings of uncertainty.

Other research confirms the feelings of uncertainty in healthcare providers: they do not like to feel uncertain and, at the same time, they want to be prepared (Markey et al., 2018; Roberts et al., 2007; Torres et al., 2016). The key is to question why healthcare professionals are often afraid of a spontaneous or impulsive reaction they may have. Roberts (2007) calls this ‘white fears’; and in this research, medical students fear unintentionally offending someone during a discussion about race. DiAngelo (2011) explains this ‘white fragility’ in white people in North America as *“a state in which even a minimum amount of racial stress becomes intolerable, triggering a range of defensive moves. These moves include the outward display of emotions such as anger, fear, and guilt, and behaviours such as argumentation, silence, and leaving the stress-inducing situation.”*

Third, ‘othering’ is very present, in the definition and implementation of culturally-sensitive care, as results show that the healthcare professionals keep looking at ‘the other’. This othering could be considered to be unintended micro-racism by the healthcare professional: the healthcare professional is not conscious that this is racism and that it raises a barrier towards the patient and his family (Torres, 2006). If healthcare professionals can overcome othering, it can help them to better understand their own biases and assumptions that might hamper intercultural interaction and reciprocal trust(Alpers, 2018; Guttormsen, 2018). This is also confirmed in other research, where it is stated that a patient’s needs can go unmet as a result of misunderstandings caused by otherness(Berdai Chaouni et al., 2020; Berdai Chaouni & De Donder, 2019; Torres et al., 2016).

The fact that the balance of power plays a role should also be considered. This can be the relationship between white Western healthcare professionals and non-Western immigrant patients, where certain assumptions are present (e.g. the expectation that patients and families with a migration background lack knowledge) (Milberg et al., 2016). This also plays a role in the frame of reference of all parties involved, and by consequence in the communication between the healthcare provider and the patient, in which there is apparently room for debate, but ultimately the rules of the healthcare professional or organisation determine the flow. This was also confirmed by ethnic minority medical students in the study conducted by Roberts (2007), where the ‘us and them’ feelings made the students uncomfortable towards white patients and white fellow students. Being more aware of one’s own frame of reference and that of the patient leads to other actions and other skills. Interactive learning methods like intervision, reflective exercises, peer learning or simulations could be helpful to achieve this goal (Kılıç & Sevinç, 2018; Leung et al., 2020; Oikarainen et al., 2019)..

3.4.1 Limitations

Certain limitations can be identified in this study. First of all, a combination of focus groups and individual interviews was used in the study. It would have been preferable to have all participants participate in a focus group session. Because of organisational reasons the physicians participated in individual interviews, in which the group dynamics of a focus group was missing, which could have modulated responses (Beck & Polit, 2014). However, those interactions gave rich accounts and, it should be noted, the discourses were rather coherent with the focus groups’ data. It is acknowledged that transferability is a challenge, but that is not the ultimate goal of this qualitative study (Bernard & Bernard, 2000).

Focus groups are an effective means of developing ideas expressed by individuals (Beck & Polit, 2014). Few disagreements emerged during the focus groups, and in general the participants had rather similar opinions and experiences.

Second, all participants voluntarily participated in a focus group on the theme of culturally-sensitive care, which may involve a selection bias with participants already having an interest in the topic of culturally-sensitive care. Even acknowledging this selection bias, it is interesting to see the the rather narrow focus of the concept and the presence of othering and racial expressions throughout the focus groups and interviews. Sorensen (2017) suggests that – to achieve culturally-competent care – it is essential to engage all stakeholders and ensure diversity among the stakeholders in order to set up a process with both a bottom-up and a top-down approach. Further study could provide further insight. Moreover, it would be interesting to study different learning methods in developing cultural awareness and awareness of othering. Finally, further research could focus on including healthcare professionals and students who do not have a particular interest in the topic of culturally-sensitive care.

3.5 Conclusion

The cultural competence of healthcare professionals and future healthcare professionals is of utmost importance) for the quality of care provided to patients worldwide.

In this study, it is shown that healthcare professionals and students share a rather narrow definition and perception of the concept of culturally-sensitive care.

A key point in our research is that healthcare professionals primarily use their own frame of reference to plan their work and care, finding it a challenge to empathise with other frames of reference, which is sometimes the case with patients. ‘Othering’ is a key specific example of our findings, which opens the door to difficulty and potential conflict in the health field. Cultural awareness and sensitivity are needed to reflect upon implicit biases and their impact on the provision of care in practice. This is essential to overcoming narrow definitions and obstinate stereotypes that may be associated with certain groups and to moving towards real implementation of proper culturally-sensitive care. Interactive learning methods could possibly play a role in the development of awareness in healthcare professionals towards othering and its potential consequences, particularly for their patients/clients with an ethnic-minority background, but further research in that field is needed.

It can be concluded that the puzzle piece doesn’t fit: even with the best intentions of healthcare providers, othering and unintended stereotyping keep setting up barriers between the healthcare staff and the patient, who relies on the healthcare offer.

References

Agency Internal Affairs. (2018). *Lokale inburgerings- en integratiemonitor Brussel*. https://www.statistiekvlaanderen.be/sites/default/files/docs/LIIMBR-Brussel.pdf

Almutairi, A. F., Adlan, A. A., & Nasim, M. (2017). Perceptions of the critical cultural competence of registered nurses in Canada. *BMC Nursing*, *16*, 1–9. https://doi.org/10.1186/s12912-017-0242-2

Alpers, L.-M. (2018). Distrust and patients in intercultural healthcare: A qualitative interview study. *Nursing Ethics*, *25*(3), 313–323. https://doi.org/10.1177/0969733016652449

Beck, C. T., & Polit, D. F. (2014a). *Essentials of nursing research. Appraising evidence for nursing practice* (Campus Jette - GEZ 613.2; 8e ed.). Wolters Kluwer.

Beck, C. T., & Polit, D. F. (2014b). *Essentials of nursing research. Appraising evidence for nursing practice* (Campus Jette - GEZ 613.2; 8e ed.). Wolters Kluwer.

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*, 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Berdai Chaouni, S., & De Donder, L. (2019). Invisible realities: Caring for older Moroccan migrants with dementia in Belgium. *Dementia (London, England)*, *18*(7–8), 3113–3129. https://doi.org/10.1177/1471301218768923

Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*, *101*, 103413. https://doi.org/10.1016/j.ijnurstu.2019.103413

Bernard, H. R., & Bernard, D. H. R. (2000a). *Social Research Methods: Qualitative and Quantitative Approaches*. SAGE.

Bernard, H. R., & Bernard, D. H. R. (2000b). *Social Research Methods: Qualitative and Quantitative Approaches*. SAGE.

Brondolo E, Gallo LC, & Myers HF. (2009). Race, racism and health: Disparities, mechanisms, and interventions. *Journal of Behavioral Medicine*, *32*(1), 1–8. https://doi.org/10.1007/s10865-008-9190-3

Burchum, J. L. R. (2002a). Cultural competence: An evolutionary perspective. *Nursing Forum*, *37*(4), 5–15.

Burchum, J. L. R. (2002b). Cultural competence: An evolutionary perspective. *Nursing Forum*, *37*(4), 5–15.

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal*, *204*(8), 429–432. https://doi.org/10.1038/sj.bdj.2008.292

Burnard, Philip. (1991). A method of analysing interview transcripts in qualitative research. *Nurse education today*, *11*(6), 461–466.

Cai, D., Kunaviktikul, W., Klunklin, A., Sripusanapan, A., & Avant, P. K. (2017). Identifying the essential components of cultural competence in a Chinese nursing context: A qualitative study. *Nursing & Health Sciences*, *19*(2), 157–162. https://doi.org/10.1111/nhs.12308

Campinha-Bacote, J. (2002). The Process of Cultural Competence in the Delivery of Healthcare Services: A Model of Care. *Journal of Transcultural Nursing*, *13*(3), 181–184. https://doi.org/10.1177/10459602013003003

Campinha-Bacote Josepha. (1999). *A Model and Instrument for Addressing Cultural Competence in Health Care*. 203–207.

Cross, T. L., And Others, & Georgetown Univ. Child Development Center, W., DC. CASSP Technical Assistance Center. (1989). *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed* (CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Rd., N.W., Washington, DC 20007 ($8.50).).

Davidhizar, R., Bechtel, G., & Giger, J. N. (1998). A Model to Enhance Culturally Competent Care. *Hospital Topics*, *76*(2), 22–26. https://doi.org/10.1080/00185869809596495

DiAngelo, R. (2011). White Fragility. *The International Journal of Critical Pedagogy*, *3*(3). http://libjournal.uncg.edu/ijcp/article/view/249

Fadil, N. (2019). The Anthropology of Islam in Europe: A Double Epistemological Impasse. *Annual Review of Anthropology*, *48*(1), 117–132. https://doi.org/10.1146/annurev-anthro-102218-011353

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001

Green-Hernandez, C., Quinn, A., Denman-Vitale, S., Falkenstern, S., & Judge-Ellis, E. (2004). *Making Nursing Care Culturaily Competent*. *29*(6), 49–55.

Guttormsen, D. S. A. (2018). Advancing Otherness and Othering of the Cultural Other during “Intercultural Encounters” in Cross-Cultural Management Research. *International Studies of Management & Organization*, *48*(3), 314–332. https://doi.org/10.1080/00208825.2018.1480874

Hart, P. L., & Mareno, N. (2014a). Cultural challenges and barriers through the voices of nurses. *Journal of Clinical Nursing*, *23*(15/16), 2223-2233 11p. https://doi.org/10.1111/jocn.12500

Hart, P. L., & Mareno, N. (2014b). Cultural challenges and barriers through the voices of nurses. *Journal of Clinical Nursing*, *23*(15/16), 2223-2233 11p. https://doi.org/10.1111/jocn.12500

Hopkins, A. F., Kooken, W. C., & Winger, E. N. (2020). Inclusive Clinical Practice and Policy for Muslim Nursing Students. *Journal of Transcultural Nursing*, *31*(1), 100–106. https://doi.org/10.1177/1043659619832079

Jirwe M, Gerrish K, & Emami A. (2006). The theoretical framework of cultural competence. *Journal of Multicultural Nursing & Health (JMCNH)*, *12*(3), 6–16.

Kim-Godwin YS, Clarke PN, & Barton L. (2001). A model for the delivery of culturally competent community care. *Journal of Advanced Nursing*, *35*(6), 918–925. https://doi.org/10.1046/j.1365-2648.2001.01929.x

Kılıç, S. P., & Sevinç, S. (2018). The Relationship Between Cultural Sensitivity and Assertiveness in Nursing Students from Turkey. *Journal of Transcultural Nursing*, *29*(4), 379–386. https://doi.org/10.1177/1043659617716518

Lafleur Jean-Michel, Marfouk Abdeslam, & Fadil Nadia. (2018). *Migratie in België in 21 vragen en antwoorden*. https://orbi.uliege.be/bitstream/2268/225608/1/Boek_21vragen.pdf

Leininger, M. (1993). Towards Conceptualization of Transcultural Health Care Systems: Concepts and a Model. *Journal of Transcultural Nursing*, *4*(2), 32–40. https://doi.org/10.1177/104365969300400206

Leung, D. Y. L., Chan, E. A., Wong, A. K. C., Reisenhofer, S., Stenberg, M., Pui Sze, C., Lai, K. h., Cruz, E., & Carlson, E. (2020). Advancing pedagogy of undergraduate nursing students' cultural awareness through internationalization webinars: A qualitative study. *Nurse Education Today*, *93*. https://doi.org/10.1016/j.nedt.2020.104514

Luiking, M., Heckemann, B., Ali, P., Doorn, C., Ghosh, S., Kydd, A., Watson, R., & Patel, H. (2019). Migrants' Healthcare Experience: A Meta-Ethnography Review of the Literature. *Journal of Nursing Scholarship*, *51*(1), 58–67. https://doi.org/10.1111/jnu.12442

Markey, K., Tilki, M., & Taylor, G. (2018). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *27*(1–2), e259–e268. https://doi.org/10.1111/jocn.13926

Milberg, A., Torres, S., & Ågård, P. (2016). Health Care Professionals' Understandings of Cross-Cultural Interaction in End-of-Life Care: A Focus Group Study. *PloS One*, *11*(11), e0165452. https://doi.org/10.1371/journal.pone.0165452

Oikarainen, A., Mikkonen, K., Kenny, A., Tomietto, M., Tuomikoski, A.-M., Meriläinen, M., Miettunen, J., & Kääriäinen, M. (2019). Educational interventions designed to develop nurses' cultural competence: A systematic review. *International Journal of Nursing Studies*, *98*, 75–86. https://doi.org/10.1016/j.ijnurstu.2019.06.005

Papadopoulos, I., & Lees, S. (2002). Developing culturally competent researchers. *Journal of Advanced Nursing*, *37*(3), 258–264. https://doi.org/10.1046/j.1365-2648.2002.02092.x

Resnicow, K., Baranowski, T., Ahluwalia, J. S., & Braithwaite, R. L. (1999). Cultural sensitivity in public health: Defined and demystified. *Ethnicity & Disease*, *9*(1), 10–21.

Roberts, J. H., Sanders, T., & Wass, V. (2007). Students' perceptions of race, ethnicity and culture at two UK medical schools: A qualitative study. *Medical Education*, *0*(0), 071103042721001-??? https://doi.org/10.1111/j.1365-2923.2007.02902.x

Sagar, P. L. (2011). *Transcultural Nursing Theory and Models: Application in Nursing Education, Practice, and Administration*. Springer Publishing Company.

Seeleman C, Suurmond J, & Stronks K. (2009). Cultural competence: A conceptual framework for teaching and learning. *Medical Education*, *43*(3), 229–237. https://doi.org/10.1111/j.1365-2923.2008.03269.x

Shen, Z. (2015). Cultural Competence Models and Cultural Competence Assessment Instruments in Nursing: A Literature Review. *Journal of Transcultural Nursing*, *26*(3), 308.

Shepherd, S. M., Willis-Esqueda, C., Newton, D., Sivasubramaniam, D., & Paradies, Y. (2019). The challenge of cultural competence in the workplace: Perspectives of healthcare providers. *BMC Health Services Research*, *19*(1), 135. https://doi.org/10.1186/s12913-019-3959-7

Sturm, G., Bonnet, S., Coussot, Y., Journot, K., & Raynaud, J.-P. (2017). Cultural Sensitive Care Provision in a Public Child and Adolescent Mental Health Centre: A Case Study from the Toulouse University Hospital Intercultural Consultation. *Culture, Medicine & Psychiatry*, *41*(4), 630–655. https://doi.org/10.1007/s11013-017-9538-7

Sumpter, D. F., & Carthon, J. M. B. (2011). Lost in Translation: Student Perceptions of Cultural Competence in Undergraduate and Graduate Nursing Curricula. *Journal of Professional Nursing*, *27*(1), 43–49. https://doi.org/10.1016/j.profnurs.2010.09.005

Suurmond, J., Seeleman, C., Rupp, I., Goosen, S., & Stronks, K. (2010). Cultural competence among nurse practitioners working with asylum seekers. *Nurse Education Today*, *30*(8), 821–826. https://doi.org/10.1016/j.nedt.2010.03.006

Taylor, R. (2005). Addressing barriers to cultural competence. *Journal for nurses in staff development : JNSD : official journal of the National Nursing Staff Development Organization*, *21*(4), 135–142.

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Torres, S. (2006). Elderly Immigrants in Sweden: 'Otherness' Under Construction. *Journal of Ethnic & Migration Studies*, *32*(8), 1341–1358. https://doi.org/10.1080/13691830600928730

Torres, S., Ågård, P., & Milberg, A. (2016). The 'Other' in End-of-life Care: Providers' Understandings of Patients with Migrant Backgrounds. *Journal of Intercultural Studies*, *37*(2), 103–117. https://doi.org/10.1080/07256868.2016.1141756

Turner, L. (2005). Is cultural sensitivity sometimes insensitive? *Canadian Family Physician Medecin De Famille Canadien*, *51*, 478.

UN Migration. (2019). *World Migration Report 2020* (World Migration reports, p. 496). International Organization for Migration. International Organization for Migration

Uzun, Ö., & Sevinç, S. (2015). The relationship between cultural sensitivity and perceived stress among nurses working with foreign patients. *Journal of Clinical Nursing*, *24*(23–24), 3400–3408. https://doi.org/10.1111/jocn.12982

Weber, R. P. (1990). *Basic Content Analysis*. SAGE.

Chapter 4: Barriers and facilitators in providing care for patients with a migration background

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Abstract

Aims and objectives

The aim of this study is to identify the barriers and facilitators experienced by healthcare professionals while caring for patients with a migration background.

Background

People with a migration background often face several structural inequalities and barriers in terms of accessibility to, and affordability of, healthcare. In order to provide quality care for patients with a migration background, it is important to understand which barriers healthcare professionals experience that prevent them from providing care and which factors can facilitate this.

Design and methods

Qualitative research following the COREQ criteria. A total of six focus groups (n = 37) and twelve individual interviews were conducted with a multi-disciplinary sample: doctors, nurses, social workers, and occupational therapists. Nursing and medical students were also included. Thematic content analysis was used.

Results

Key findings suggest that the main barrier is that healthcare professionals regard people with a migration background as 'the other'. Healthcare professionals do not feel secure or competent to provide care for these 'others'. According to the healthcare professionals, the hospital structures – and, particularly, the managerial instances – appear to be only slightly supportive. Structural barriers at the level of the healthcare system, such as limited implementation of care coordination and austerity measures (time pressure or economic restrictions), were also perceived as barriers. Facilitators can be the healthcare professionals' attitude or the flexibility of the management.

Conclusions

Healthcare professionals experience barriers in caring for people with a migration background. Othering plays a key role in building or maintaining several barriers. A multilevel approach is necessary to tackle these barriers and enable facilitators.

Relevance to clinical practice

Raising awareness about ‘othering’ in the educational programs of students and healthcare professionals is essential. Also, deploying support mechanisms and valuing the competences of multicultural and multilingual healthcare professionals can help facilitate quality care for patients with a migrant background.

Keywords

Patient with migration background, healthcare professionals, healthcare providers, management, healthcare organisation, barriers, facilitators

4.1 Introduction

In order to 'leave-no-one-behind', irrespective of their migration status, the Sustainable Development Goals urge for more evidence-informed health responses that engage with migration (Wickramage et al., 2018). As a fact, people with migration background often face several structural disadvantages, inequalities and barriers in terms of accessibility to, and affordability of, healthcare (Berdai Chaouni, 2021; Scheppers et al., 2006). Racial and ethnic minorities of migrant background face unfavourable social determinants of health – such as lower education, lower housing quality, and living in disadvantaged areas – which also decrease accessibility to care (Nair & Adetayo, 2019). In addition, it is known that healthcare professionals find it challenging to provide care to people with a migrant background (Claeys et al., 2020; Markey et al., 2018). These challenges are reinforced by the lack of organizational support that exists in delivering care for ethnic-diverse patients (Claeys et al., 2020; Narayanasamy, 2003). Finally, migrants and ethnic minority groups seem to make poorer use of healthcare services (Nielsen & Krasnik, 2010; Uiters et al., 2006). This is important to note, because adequate use of healthcare services is an important precondition for health in general (Wickramage et al., 2018).

If the ultimate purpose is to provide accessible and high-quality healthcare for people with a migration background, it is important to understand which barriers healthcare professionals experience that prevent them from providing this quality care, or which facilitators enable this. Taking this purpose into consideration, the aim of this study is to identify the potential barriers and facilitators that healthcare professionals experience in providing care to patients with a migration background.

4.1.1 Background

Healthcare providers struggle with the implementation of care for patients with a migration background (Claeys et al., 2020; Markey et al., 2018). A study by Taylor and Alfred (2010) showed that healthcare professionals perceived caring for ethnoculturally diverse clients as both challenging and frustrating. The literature identifies barriers and facilitators to providing quality care for people with a migration background on 3 different levels within the healthcare system: the individual and interpersonal level, the level of management and the organisation, and the level of the healthcare system.

A number of barriers can be identified both at the individual level of the healthcare professionals' (such as uncertainty regarding their own competences) and at the interpersonal care relationship with the patient (for instance, discriminatory perception towards 'others'). A barrier that can be identified is the healthcare provider's limited linguistic proficiency in a given foreign language (Scheppers et al., 2006). Professionals seem to have certain objections concerning the role of translators to overcome language barriers (Claeys et al., 2020; Suurmond et al., 2016). Communication is more than mere language, and professionals maintain that a patient's lower educational level (Scheppers et al., 2006) and lower social status (Smith et al., 2000) can lead to ineffective communication between the patient and the healthcare provider (Suurmond et al., 2016). Moreover, professionals seem to hold stereotypical attitudes towards patients with a migration background (Claeys et al., 2020), yet are unaware that this can influence the trust relationship between the patient and the professional and can equally influence the care process (Berdai Chaouni et al., 2020; Carlsson & Pijpers, 2020). Conversely, the literature also describes several factors – such as cultural awareness (Grandpierre et al., 2018), well-developed social skills, and self-awareness – that facilitate the caregiver in providing quality care to persons with a migrant background (Berg et al., 2019). In addition, it is also important that the professional be able to provide respectful person-centred care (Jones et al., 2017) and understand and can deal with the expectations of the patient (Harrison et al., 2020). Finally, research also shows that bicultural professionals can facilitate the alignment of health programs with culturally and linguistically diverse communities (Cyril et al., 2017).

On a second level, there are barriers at the level of the management of the care organization. Healthcare professionals do not work alone often, but in a team or a care organization with a specific vision, policy, management and culture. This also plays a role in the barriers that professionals experience. Dell'Aversana and Bruno (2021) point out that resistance and hesitation in the organization are the main barriers in providing care for patients with a migration background. On the other hand, cultural awareness in the management and policy level of the organization can ensure that care provision to people with a migrant background is facilitated. This can involve the use of culturally appropriate assessment and intervention materials and support for professionals to provide tailored care that meets the needs of minority patients (Grandpierre et al., 2018). Awareness of inequalities in services and a patient-oriented care culture can also be facilitators. These factors can facilitate quality care if managers are aware of the barriers that exist in caring for people with a migrant background and if they see opportunities to improve this (Dell'aversana & Bruno, 2021).

Third, when considering barriers and facilitators on a wider scale, obstacles and enablers can equally be found at the structural healthcare system level. For example, time restrictions and austerity measures increase the workload for care providers (Scheppers et al., 2006). Staff shortage limits the possibilities for professionals to provide person-centred care (Barrett et al., 1998). Consultations and treatments that are carried out in an abrupt and quick manner can lead to miscommunication and distrust (Smith et al., 2000). Referral between different care services, or between primary care and more specialized care, can be experienced as barriers to providing good care to persons with a migrant background. General practitioners can facilitate referrals and make it easier for patients to go from primary care to more specialized care. Efforts and interventions to make healthcare more accessible to certain minority groups must consider economic, geographic and social factors (Jones et al., 2017).

Taking this information into account, it is necessary to better understand which multilevel factors in daily practice play a role in facilitating or hindering quality care provision for persons with a migration background: on the individual and interpersonal level of the healthcare professional, the level of management and organisation, and the healthcare system level. In response, the following research question is highlighted in this study: Which facilitators and barriers do healthcare professionals experience in providing care for patients with a migration background?

4.2 Methods

This study is part of the larger Diverse Elderly Care research project, which examines culturally sensitive dementia care for migrants in Brussels, from the perspectives of patients, family carers and healthcare professionals. In particular, this paper explores in depth the barriers and facilitators in providing care to patients with a migration background, but from the perspective of the healthcare professional.

4.2.1 Study design and procedure

A series of focus group (FG) interviews and individual interviews were conducted with healthcare professionals and students. The aim of the FG interviews was to explore the different barriers and facilitators in providing care for patients with a migration background. The use of individual interviews allowed us to study the barriers and facilitators in more depth. All interviews were analysed using a Thematic Content Analysis as described by Burnard (2008). A descriptive qualitative approach was deemed most suitable for exploring the professionals' views on barriers and facilitators for culturally sensitive care (Beck & Polit, 2014; Bernard & Bernard, 2000). We followed the EQUATOR COnsolidated criteria for REporting Qualitative research (COREQ) checklist guidance to report the method of our study (Tong et al., 2007). Ethics approval was granted by the Ethics Committee of the University Hospital of Brussels (CE 2016-105).

A total of six FG interviews (n=37) and 10 'individual' interviews (n=12; 2 interviews were held with two respondents for practical reasons) were conducted with healthcare professionals. Having experience in care (as a job or from an internship) in a diverse city (e.g., Brussels) was the inclusion criteria for all participants. Respondents were selected by using consecutive sampling for the FGs and purposive sampling for the individual interviews. The (interview) participants were recruited from a network of professionals in Brussels and were invited by e-mail and telephone by the first or second author. Their contact details were collected through the professional network of the first and second author and respondents indicated their willingness to participate in the study. All confidential process was respected, and special care was taken into ensuring data protection and GDPR. The FGs participants were invited face-to-face during a seminar or during class. Data collection took place between November 2017 and January 2019. All interviews were scheduled at a time that was convenient for the participants, and the interviews were audio taped after obtaining verbal informed consent at the beginning of each interview. The FG interviews took place in a meeting room at a university college or at a hospital in Brussels. The individual interviews took place at the individual offices or meeting rooms of the healthcare provider and were conducted in Dutch or French. Both interviewers spoke the two languages. Table 1 and Table 2 provide an overview of general demographic information of the participants. There were four all-female FGs and two groups with male and female participants. In the individual interviews, there was also a feminine majority with nine female participants compared to 3 males. The participants of the FG sessions were relatively young, with an average age per group between 19 (students) and 36 (nurses).

Table 2: Overview of demographic information of the participants in the FG sessions.

	Number of participants	**Profile of the participants**	**Sex**	**Mean age**
FG1	7	Intercultural mediators	female	34y
FG2	5	Multidisciplinary geriatric team	female	32y
FG3	7	Nurses	female	36y
FG4	6	Nursing students	female	19y
FG5	8	Nursing students	mixed	20y
FG6	4	Medical students	mixed	21y

Table 3: Overview of demographic information of the participants in the individual interviews (INT).

	Profile of the participant	**Sex**	**Age range**
INT1	2 social workers in a hospital	Female	30-35
INT2	Social worker in a healthcare organisation	Female	40-45
INT3	Geriatrician in a hospital	Female	35-40
INT4	Neurologist in a hospital	Male	40-45
INT5	Neurologist in a hospital	Male	40-45
INT6	General practitioner	Male	30-35
INT7	Carer in a long-term care facility	Female	40-45
INT8	Social worker in a care organisation	Female	50-55
INT9	2 home-care nurses	Female	40-45
INT10	Occupational therapist in a long-term care facility	Female	35-40

Data saturation was reached by the 7th interview because of the richness of the data, meaning that additional data did not lead to new emerging themes as it tended to reinforce the previous findings (Saunders et al., 2018). The interview guide, based on the literature review, was used to structure the interviews. The interview started with an ice-breaker question: “Could you please clarify what is good (quality of) care according to you?”. Thereafter, participants were asked to share their opinions regarding the following topics:

1) How do you define and perceive culturally sensitive care (in theory and in practice)?

2) How do you (try to) provide culturally sensitive care in practice?

3) What are facilitators for, and barriers to, providing care for patients with a migration background?

4) What is the role of the patient and the healthcare organisation in culturally sensitive care?

The answers to questions 1 and 2 were covered in a previously published paper (Claeys et al., 2020). The answers to questions 3 will be addressed in the current paper. In order to not influence the perception of the participants regarding the topic, no *a priori* definition or description of culturally sensitive care was provided. After each session, a debriefing report was made by the main author, including observational notes and comments about the process.

4.2.2 Analysis

All interviews were audiotaped, and an official transcription office transcribed them verbatim and field notes were made during the interviews. Thematic content analysis was used to analyse data, following the stage-by-stage process of Burnard's model (Bengtsson, 2016; Burnard et al., 2008). The central aim of this thematic content analysis is to classify data into more relevant and manageable parts or themes, which makes this methodological framework suitable for exploring barriers and facilitators on different levels of the healthcare system (Weber, 1990). Data was coded by the main author, using the qualitative data analysis software MAXQDA©. The coding tree was built following the main themes used by the interview guide. After initial coding, the authors discussed data coding. A second round of analysis led to a classification of barriers and facilitators on 3 different levels concerning the care system: namely, the level of the healthcare professional, the level of the management, and the level of the healthcare organization. These findings were again discussed by the research team. A third round of analysis led to the findings presented below.

4.2.3 Research team and reflexivity

The first and second authors conducted the FGs and interviews. Both researchers have experience in the field of qualitative research methods, organisation of healthcare and management, and culturally sensitive care. All authors have experience in qualitative research methods and thematic content analysis, and all are lecturers in a healthcare or research program. The two researchers who collected the data reflected comprehensively on their position and their role leading to potential biases during the research process. At the beginning of each interview or focus group session, the researchers introduced themselves. The participants were informed of the purpose of the study, the course of the study, the logic of the session, and the ethical and privacy terms. Participants were reassured that anonymity and confidentiality was guaranteed, as no names were traceable in the transcriptions since numbers were used as substitutes. With the informed consent, the participants also received the contact details of the researchers.

4.3 Results

This section presents the barriers and facilitators that participants experienced in providing care for patients with a migration background, as mapped by the data analysis: barriers and facilitators experienced a) at the healthcare professionals' level, b) on the level of the management of the care organisation, and c) at the level of the healthcare system. These results underline the barriers and facilitators as perceived by the healthcare professional, even when factors are defined at the management or healthcare system level. The study participants were asked about their care for patients with a migration background, but in most cases, the respondents talked about patients with a non-western background, and, more specifically, about Muslim patients. Therefore, the results below should be considered from that perspective.

Main findings show that healthcare professionals see people with a migration background as 'the other'. This othering shapes and externalises the barriers that healthcare professionals experience in providing care. Healthcare professionals do not feel secure or competent to provide care for these 'others'. According to the healthcare professionals, the hospital structures – and, particularly, the managerial instances – appear to be only slightly supportive. Structural barriers at the level of the healthcare system, such as limited implementation of care coordination and austerity measures (time pressure or economic restrictions), were also perceived as barriers.

4.3.1 Barriers and facilitators experienced at the healthcare professionals' level

Participants reported barriers experienced by themselves or by their colleagues: uncertainty about their own competences in providing care for patients with a migration background, discriminatory perceptions, and discriminatory behaviours. The facilitating factors mainly concern the critical self-awareness and attitude of the healthcare professional.

Uncertainty regarding their own competences in providing care for patients with a migration background

The student participants indicated that it felt difficult to deal with situations or conflicts in which they were confronted with issues related to ethno-cultural differences or that involved racism. They reported they had insufficient skills for interacting with patients with diverse backgrounds and felt insecure about handling these situations. Also, student participants reported that, during their programs, cultural issues were discussed in a very stereotypical way, by zooming in on certain characteristics of a certain population group (e.g., 'the' Muslim patient, 'the' Jewish patient, 'the' Chinese patient). The student participants indicated that the ethnic-cultural diversity in the classroom was not actively taught as an added value during the lessons, for instance to provide examples or providing a broader vision when exploring specific topics. According to them, this could have been the starting point to exchange personal experiences which could lead to more openness towards each other. In addition, the student participants felt too few tools were given to deal with situations in practice, as the next quote illustrates:

> *"We did learn something about culturally sensitive care, but not enough to be able to work very well with that." (Nursing student, FG)*

Also, the students (participants) emphasized that sometimes during their internships, they felt vulnerable which limited their ability to appropriately react when they felt a difficult situation arose. This would be linked to their role as a student and the fact that subsequently their evaluation depended on the professionals that may have been confronted due to an incorrect management.

In addition, students indicated that they also felt insecure and uncertain regarding their own competences when considering caring for patients with a non-western background. This feeling of insecurity obstructed a natural approach to their care. They also underlined that they had little knowledge to deal with 'other cultures' and they had received too little education or guidance during their programs on how to work with patients with a migration background. The quote below illustrates this.

> *"I recently had someone [with a migration background] who was diagnosed with high blood pressure, and he asked me "what is blood pressure?" Then you are sitting there and ... [participant sighs] okay, how do you explain that? Usually, people experience this intuitively. They have heard something from someone else, but now you have to explain it in a different way." (Medical student, FG)*

Moreover, experienced participants felt insecure when interacting with patients who do not speak or understand the dominant language, or who have a different communication style than the healthcare professional. Although the participants saw a solution to overcome this barrier in working with interpreters, the participants indicated that they perceived working with external interpreters as difficult and cumbersome. Working with (official and informal) interpreters is often not done because of the following reasons: (1) limited trust from the healthcare professional to work with interpreters, (2) practical feasibility (i.e., scheduling a meeting with the interpreter together with the patient; administration and/or payment of the interpreter), and (3) the position and role of the healthcare professional, where the healthcare professional must be prepared to let something be out of their hands. The next quotes illustrate this hesitation:

> *"What if the interpreter mistranslates it?" (Nurse, FG)*
>
> *"[working with a professional interpreter] is a hassle ... often you can't do that ... how to time on a test when there is also a need to be translated? ... What if the patient doesn't show up?" (Doctor, interview)*

Discriminatory perception of healthcare professionals towards 'others'

The practice of thinking in terms of 'us and them' and othering – i.e., micro-racism by defining *the other* in an inferior way (Dervin, 2016; Fleras, 2016) – was present throughout the whole discourse of the interviews and focus groups, and was especially noticed in opinions and statements such as 'we' and 'they', 'they are different', 'that is also the case with *normal* people, not just with them', 'ordinary people', 'they have to adapt', and so on. Participants spoke of people with a migration background, even if they were second or third generation, in terms of 'a guest', a temporary situation, or they made the comparison with a situation where one is on a holiday trip in a foreign country. Also, other terminology like 'integration', 'to westernize', 'knowing *the* language', etc. shows that participants position themselves within a superior framework and perceive the migrant patients in a more inferior framework. This type of comments was mainly present among professionals that had no migration background themselves. In general, healthcare professionals with a migration background used a more nuanced discourse, and the perceived otherness was directed towards patients with migration roots in another region (for example, Central Africa or Eastern Europe).

Some participants – students and experienced workers – stated that it was sometimes good to have some prejudices. These participants saw this as a preparation for certain situations and used the prejudices to handle their uncertainty, as the next quote shows:

> *"I don't think it is bad to have a little prejudice. In our society, prejudices are seen as something very negative, and you should not judge anyone. But I think that, very often, these prejudices are correct. When you have someone from a certain culture, maybe there will be some of those people who don't mind you extending your hand to them, but you have 95 out of 100 who do. And they may find that a really big problem." (Medical student, FG)*

These prejudices led to thinking in stereotypes towards patients with a migration background, as the following quote illustrates:

> *"Usually, these women are at home and then, during the day, they are busy with their parents and in the evening, they go and get the children from school – they really live among each other. These social contacts are there [within their own community] … Those families take care of each other. Like I say, usually the women are at home, mostly unemployed."* (Social worker, interview)

Moreover, participants saw patients with a migration background in the stereotypical image where the family takes care of the patient. Participants therefore concluded that certain care solutions (e.g., care provision in a long-term care facility) would not be accepted because of cultural norms – and so they hesitated to propose care solutions, based on the preconception that they would not be accepted anyway.

Discriminatory behaviour of healthcare professionals towards 'others'

In addition to the discriminatory perceptions, student participants described discriminatory and racist behaviour by fellow caregivers or by internship counsellors towards patients and colleagues with a migration background, as the following quotes also illustrate:

> *"At my last internship, I was on my way to the waiting room to fetch a patient. A nurse grabbed me by the arm [and said] 'You shouldn't put too much time in that black one.' … And afterwards I was typing my report and then she came back to me [and said] 'It was a typical black one again for sure?' Just because it was someone with a black skin colour, that doesn't mean that they don't deserve the care I'd give to someone else. So, I was pretty worked up about that. Or another colleague who said: 'We're not going to give the Wi-Fi password to strangers [= patients with a migration background].'" (Medical student, FG)*

> *"There was a man, but the nurse could not communicate with him. ... But I knew he was Muslim and so I said, ‘That's meat, he can't eat that.’ The nurse said, ‘yes, but he doesn't know that.’ And she said to me, ‘yes, give it.’ And I said, ‘No, I am not giving him that. Is there some bread I can give him?’ And then the nurse got mad at me because I just had to give the meat to him. I just don't agree with that. I knew he was Muslim, and he was repeating ‘no meat’ “. (Nursing student, FG)*

There was a strong focus on Islam and on Muslim patients: next to the illustrated islamophobia, the care was adapted to what is believed to be desirable for ‘the Muslim’. The religion, and religion-bound wishes, preferences and needs were not discussed with the patient. These were assumed on the basis of the name or the appearance of the patient and were filled in very generally, based on general stereotypical ideas about 'the Muslim’, as the following quote illustrates:

> *“A woman who had requested vegetarian meals and who had a Moroccan-sounding name, she [the nurse] had changed the meal preference to 'halal'.” (Nursing student, FG)*

Facilitators at the level of the healthcare professional

An aspect often cited as a facilitator was the healthcare professional’s attitude: an openness to the patient's background, respect for self-esteem, with attention to the needs of the patient with a migration background, openness and willingness of the individual care provider to see what options there are to meet the patient’s needs, to deal with this in a creative way and to think outside the box. Healthcare professionals’ skills in asking questions and engaging in an open conversation can also facilitate quality care for patients with a migration background, with self-awareness of their own frame of reference and critical awareness of (societal and own) stereotypes and prejudices. The participants indicated that one needs to be aware that there are intracultural differences, that education level, literacy, social network, etc. also influence a person, and that not everything can be reduced to the cultural difference.

> ‘*It is about treating people the way you yourself want to be treated.’* (Nurse, FG)

Finally, the “multilingualism” of the healthcare professional can also be a facilitator in the care for patients with a migration background, although at times could be challenging. The participants indicated that it is a common practice to call upon a multi-lingual colleague when translation for a patient or a relative is required. Therefor the availability of a multilingual colleague is seen as an asset or a facilitator. For the multi-lingual colleagues however, this is an extra challenge or task on top of the already heavy workload.

> *“But they [professionals] never use them [official interpreters]. For example, I had a patient who spoke Arabic and they just asked me ‘can you translate?’ But I was doing something else. I shouldn't, I am not a translator and even though I can speak Arabic... One just has to call an interpreter, but yes... that takes too much time.” (Nursing student, focus group)*

Moreover, multi-lingual participants reported that, if they spoke a language other than Dutch or French with a patient on their own initiative or if they suggested this, they sometimes received negative comments from non-multi-lingual healthcare professionals or they were ignored.

4.3.2 Barriers and facilitators experienced on the level of the management of the care organisation

The most common barriers they experienced were lack of leadership and guidance and lack of organisational policy towards situations in which patient and healthcare professional –from different ethnic-cultural backgrounds – interact with each other. Facilitators at the management level were mainly structural conditions that allowed the healthcare professional to be more flexible towards the needs of the patients.

Lack of leadership and guidance towards culturally sensitive care

The answers of the respondents indicated that, in both employment situations (working in their own practice or working as an employee), they experienced a lot of individual responsibility in deciding how far they could go to meet the needs of the patient in certain situations. The study participants reported that they perceived a lack of support from their employer to deal with certain situations in which they felt insecure about care provision related to a patient with a particular migration background. At the same time, respondents stated that they perceived little flexibility in care organisations for the healthcare professional to meet the needs of the patient. Professionals who, for example, deviated from visiting hours or who met the language or nutritional wishes of the patient with a migration background, were sometimes held accountable for these actions. As one participant said in an interview, they allowed relatives to enter the hospital unit during a night shift, to be with a dying patient with a migration background. Afterwards, they were reprimanded for this, by both the supervisor and some colleagues.

> *"I thought 'Let those people say goodbye' and then [afterwards] I was reprimanded. I was like, 'If you, as a large institution that cares for people, reprimand employees for such a reason…, well I thought that was bad." (Nurse, interview)*

In addition, participants emphasized that often the manager or supervisor of the team plays an important role and has an exemplary function in the way in which the team provides care for people with a migration background. As a participant said in a focus group, an in-service training on culturally sensitive care was given, and the supervisor allowed some team members to skip the training because they were not interested in the theme. The participant experienced this as a strong signal to the other team members about the importance that was attached to this theme by their supervisor or by the management and the organizational policy.

Lack of organisational policy towards culturally sensitive care

Several participants confirmed that their healthcare organisations were not prepared to consider the individual cultural or religious needs of the patient. Participants asked themselves:

> *"Why do our care organisations not offer meals buffet-style, so that everyone could choose for themselves? Why is there no neutral place for prayer? Why is it so difficult to let patients speak their mother tongue?" (Doctor, interview)*

The participants linked the need for an organisational policy on culturally sensitive care to the diversity of the patient population, and they felt it was necessary and urgent for the management to work on this theme actively within the organisation. They felt this also had an influence on the extent of expertise regarding this theme in the organization.

Participants indicated that the organisational policy, the vision and the working culture of the care organization played a role in how the individual healthcare professional approaches patients with a migration background. Some participants stated that, in an ideal situation, all aspects in the organizational structure should become culturally sensitive – e.g., the cleaning services, the professionals, and the infrastructure, amongst others. This would make it easier and more supportive for the individual healthcare professional to provide culturally sensitive care.

Facilitators on the level of the management of the care organisation

Facilitators at the management level were experienced mainly in the structural decisions that allowed individual healthcare professionals to be flexible and creative in order to meet the needs of the patient. In the quote below, the healthcare professional is given the time to go to the residential care facility himself, whether or not accompanied by the family and the patient, in order to make the best possible choice for a further care solution.

> *"At that time, we try to look for a caring home where there are people of the same nationality as the patient... For example, I think of a lady who was Turkish and finally I went to visit a caring home where I saw there was more Turkish staff." (Social worker, interview)*

Moreover, the management can facilitate or structurally support consultation meetings with the patient, the family and the healthcare professional. These meetings benefit the provision of care and the care organisation.

4.3.3 Barriers and facilitators experienced at the level of the healthcare system

Finally, there were barriers reported that are the result of structural measures or policies in healthcare, and that influence how individual care provision is provided and perceived. These barriers were difficult implementation of integrated and tailored care under pressure due to austerity and bureaucracy measures. The facilitators mentioned here also related to the division of available time in care.

Difficult implementation of an integrated care approach

Participants indicated that there were no guidelines for cooperation between organisations and individual healthcare professionals in healthcare, and by extension this would also impact social services and welfare care. The lack of guidance may lead to a problematic cooperation between professionals and local healthcare services. Participants indicated that the cooperation at a local level is flawed for the primary care services (e.g., homecare nurse, general practitioner) and for the connection to the second-line care services (e.g., hospitals). The hospital's initiatives to contact other professionals outside the hospital appeared to vary, and is mainly at the initiative of the individual healthcare professional, as the next quote illustrates:

> *"But in general [there is] not much [contact with the GP], because in general they come with a referral letter from the GP, and then I think to myself: '[the letter] will include everything that he has to say [about the patient]' ... [If the GP wants to reach us] then it is not always easy to contact us. And vice versa too. And so, we both just stay in our own cocoon." (Doctor in hospital, interview)*

Participants also described situations the caring process was dependant on individual efforts of specific individuals, for instance by being better connected or able to seek specific support. By the same token, participants claimed to be aware that this fragmented care and service offer complicated the care provision, and that this constituted a barrier for people who had less knowledge of the healthcare system, such as some people with a migration background or people in precarious situations.

Tailored care under pressure due to austerity and bureaucracy measures

Participants perceived that tailored care – and even the quality of care – was under pressure because of specific barriers in terms of the time required for administrative purposes. Also, other issues such as staff shortages, or bureaucratic issues would jeopardise correct care. Participants perceived that there was high time pressure on healthcare professionals, also reinforced by the standard-time-setting system, which prohibited them from spending extra time on additional needs of patients or the family or on additional practical tasks like translating.

> *"We currently have an average of 20 [clients] to care for during one afternoon. So, you can't take the time to listen to their story." (Social worker, interview)*

Within this limited time frame, professionals in this study seemed to focus on daily essential perfunctory tasks, rather than focusing on the person-centred needs of patients. This resulted in too much time pressure with too little staffing. As a result, there was little flexibility for dealing with patient needs that differ from the norm – for example, patients with a migration background or people in poverty, as the next quotes show:

> *"You certainly don't have to start questioning the needs [of patients with a migration background] in advance, because that's going to make it difficult for everyone, and then there's even more time pressure." (Student nurse, focus group)*

> *"The problem is, if you start questioning what [the needs are] in advance, then everyone is going to start making a fuss about care. ... Yes, better to respond at the moment than to start questioning the whole hospital. [Otherwise] the staff is going to be even more overworked." (Student nurse, focus group)*

Furthermore, although care students indicated that they have slightly more time to invest in the patient relationship than professionals in the field, they also perceived that the provided care was not always experienced as human, or it lacked human dignity, due to too much work and too little staffing.

Specifically for the organisation of home care in Belgium, the system of remuneration per task was called into question. This system ensured that nurses who performed a lot of actions/tasks also earned a lot. The question remained: what is the number of visits per day that one can provide good quality of care? Participants indicated that, as a result of this system, some nurses who consciously chose to care for fewer patients per day and take more time in order to provide sufficient quality care earned less and, therefore, bore the financial consequences for wanting to provide quality of care.

In addition, in home nurses' organisations, home visits are ended against a timetable, which meant that the nurse either had to work very quickly or that they were still working outside their paid working hours. There were also very few regulations in this field, which contributed to abuse of vulnerable patients and competition between professionals.

> *"I know of a home nurse who goes to wash people with ear plugs and music on, because 'they don't understand me anyway'." (Nurse, interview)*

Participants indicated that the way in which care was currently organised did not allow room to provide tailored person-centred care.

Facilitators at the level of organisation of healthcare

It is interesting to point out that the time factor is named as a barrier by one participant and as a facilitator by another participant, as the next quote shows:

> *"We organise a meeting where we invite the family and the doctors and other disciplines (within the team) ... The whole family is present ... in general, this is very well received. ... It comforts them ... So, it takes time, but it also facilitates in a large way." (Social worker, interview)*

Although the content of these types of interprofessional meeting were valued by the health care professionals, several healthcare professionals could not invest the necessary time to these meetings, because of their patient- and workload. Although many participants experienced the restricted time as a barrier, there were also participants who found ways to deal with this. For example, some GPs work according to the system in which the patient pays a lump sum per year instead of paying per consultation. This gave the GPs the opportunity to take more time with their patients. There were also some homecare nurses who suggested that they take more time per patient. In both examples, this way of working does have financial consequences for the healthcare provider. Certain nurses choose to spend more time per patient, and therefore earn less due to a limited patient portfolio than other colleagues who may decide to deliver a more hurried type of care.

4.4 Discussion

The aim of this study was to describe the barriers and facilitators that healthcare professionals experience when providing care to persons with a migration background. Overall, the results show that healthcare professionals think primarily in terms of barriers when it comes to taking care of patients with a migration background. Facilitators are also discussed, but they are mentioned less often and less specifically. This is in line with the results of previous research, which shows that professionals find culturally sensitive care difficult and challenging (Claeys et al., 2020; Markey et al., 2018).

The barriers and facilitators experienced at the level of the healthcare professional show, first of all, that they feel insecure about their own competences. These findings are also consistent with other research (Markey et al., 2018; McClimens et al., 2014; Tortumluoglu et al., 2006). To overcome these feelings of insecurity, our participants search for more knowledge. However, research has shown that more knowledge about cultural diversity does not ultimately lead to having more cultural competence, and education programs about cultural diversity or culturally sensitive care are perceived as stereotypical (Berdai-Chaouni et al., 2020; Seeleman et al., 2009). Additionally, following a course in an ethno-diverse class setting, or following lessons by a teacher with a migration background, does not necessarily lead to a culturally sensitive attitude among the students (Seeleman et al., 2014). Although respondents also struggle with language, they undertake only limited action to overcome this barrier (Kynoe et al., 2020; Vissenberg et al., 2018). Instead of using official interpreters, our results show the often-used practice of calling upon a multi-lingual colleague healthcare provider to come over and translate. However, the perspective of the multi-lingual colleague, the impact of this request on how this colleague is positioned, and workload are not taken into consideration. This practice raises some questions about how multilingualism is acknowledged and rewarded by fellow colleagues and the employer, or about the ambiguous attitude towards one’s own language skills and the language skills of others. Language and cultural factors seem to form a tandem whereby they can reinforce each other (Hughson et al., 2018). Language and cultural factors can also reinforce the disposition of healthcare professionals to be even more task-oriented than they already are. This allows them to minimize the relational opportunities for a meaningful and respectful communication (Small et al., 2015; Taylor & Alfred, 2010). Small et al. (2015) also suggest that the healthcare professional’s non- or under-accommodating language behaviour is linked to 2 communication predicaments: lack of understanding and devaluing the other. So here too, becoming aware of the mechanisms of ‘othering’ plays a role in overcoming this barrier.

Secondly, thinking in terms of ‘us and them’ has a major influence on how we see ‘the other’ and how we treat them (Arnaut et al., 2015). There is a rather negative attitude towards everything that is perceived as ‘the other’. This othering was highly present in the narratives in our study, and definitely illustrates the point of view with superior and inferior cultures. These ideas of racial superiority are also described in other research (Markey et al., 2012; Torres, 2006) and can be reinforced by the already present relationship of reliance between the healthcare professional and the patient. The concept of racial superiority even seems to overrule the relationship of reliance between a healthcare professional and a patient, as professionals with a migration background experience hostility from patients without a migration background, because of ethno-cultural differences (Martin-Matthews et al., 2010). In addition, during the exchanges with professionals, it becomes clear that there is a certain prevailing view among fellow professionals that culturally sensitive care is not important, which affects the individual actions of the healthcare professional, despite his/her own competences. It is a natural reflex to see the world through one’s own frame of reference, but it is important to become conscious of this point of view in order to outgrow it. That way, one becomes more conscious of the stereotypes and prejudices that were unconsciously developed at an early age (DiAngelo, 2011; Markey et al., 2012). Furthermore, in suggesting care solutions for patients, a markedly predominant biomedical framework is still present for the healthcare professional. The care solution proposed by the healthcare professional does not always correspond with the choice or the personal preferences or financial possibilities of the patient or their caregiver, which is then perceived as refusal of care, sometimes because of cultural reasons (Fatahi & Krupic, 2016; Nielsen et al., 2019). Although these factors seem universal and not only occur in patients with migration backgrounds (Piacentini et al., 2019; Rosenow, 2005), these barriers are framed as cultural barriers that are especially problematic in patients with a migration background or as barriers that are linked to a migration history (Ryan & Scullion, 2000). Our results support the concept of the *migrants’ othering* , a problem very present in Western societies (Fadil, 2019), in which the situation of ‘the other’ is always more problematic, more challenging, with lower health skills, with more refusal of care, than for persons that are not seen as ‘the other’.

Third, the results also show that discriminatory and racist behaviour in healthcare reinforces feelings of insecurity and is a very explicit and discriminatory expression of the idea of othering. In the absence of tools to deal with this, and in the absence of a communication channel for this, racist behaviour or expressions are tolerated or ignored. Denial of racist practices is a common problem, but it is particularly problematic in nursing (Markey et al., 2012), as our study also clearly illustrated.

Both the results and previous research confirm that the attitude of the healthcare professional can be a facilitator in the provision of care for patients with a migrant background. Critical self-reflection and critical self-awareness are especially important, along with an openness and attitude that demonstrate a willingness to learn (Grandpierre et al., 2018). In addition, it appears that a healthcare professional’s bi-cultural background can also help remove barriers when it comes to reaching certain target groups, although this should always be seen in combination with other competences necessary for a care provider. A healthcare professional’s multilingualism can also be a facilitator (Cyril et al., 2017).

Barriers on the level of the care organisation and its management point out that there is a lack of leadership and guidance towards culturally sensitive care and a lack of organisational policy towards culturally sensitive care when patient and healthcare professional – from different ethnic-cultural backgrounds – interact with each other. Although research has proven that the role of the care organisation and the management is very important to support the healthcare professionals in daily care practice and to strengthen structural changes (Aspinall et al., 2021; McClimens et al., 2014), our study shows that there is little support from the employer or the manager, and the responsibility to find flexible solutions or to think out of the box lies with the individual healthcare provider. Markey (2012) claims the whiteness of the care institutions goes unnoticed as the prevailing framework, which plays an important role in the deceleration of structural changes. The managers can play a facilitating role by (for example) offering a safe environment for the healthcare provider to learn and discuss situations in which they feel insecure, but also by enhancing workplace diversity and community outreach (Ogbolu et al., 2018). As already mentioned, there is the notion that the topic of culturally-sensitive care is not important, and that the cultural competence of healthcare professionals is still too little regarded as a strategic goal for the care organisation (Weech-Maldonado et al., 2018). The results also indicate that the need for a policy for a diverse patient population is experienced mostly at management level, when an increasing number of patients with a migration background make use of the organisation's healthcare offer.

At the management level, our findings emphasize that there is a need for structural support towards professionals in providing tailored patient care. This requires that the organization has awareness of inequalities in our society and that the organization has a clear vision and has a policy for person-centred care. However, this first requires a growing awareness within the policy and management of the healthcare organization (Grandpierre et al., 2018).

Finally, barriers on the level of the healthcare system were identified, such as difficult implementation of integrated care and tailored care under pressure due to austerity measures. An essential aspect of integrated care is that it must bring together fragmented key elements of the care system (Goodwin, 2016). The WHO and the UN see integrated care as an action area in the decade of healthy ageing (2021-2030) and this confirms the importance that is attached at an international policy level to an adequate integration of care and services in the professional field. For several years now, actions have been supported at various policy levels to promote integration of care services, providing more efficient collaboration and seamless care (Antunes & Moreira, 2011; UN, 2020). Nevertheless, the results show that it is precisely the lack of integration of care that appears to be a barrier for healthcare professionals in providing good care to people with a migration background. Despite good initiatives, many healthcare professionals often continue to work only in their own domain and within their own discipline, and the bridge to other care or services is not, or not sufficiently, established. Patients need access to acceptable and accessible care and welfare, but the patient must also be able to trust that those care and welfare services can correctly and supportively refer to other services that are needed to fully meet the patient's needs (Fret et al., 2019; UN, 2020).

Furthermore, austerity measures, such as economic restrictions, shortage of staff, and limited time are major limiting factors to the delivery of culturally and linguistically appropriate care services that suit the needs of every patient (Hughson et al., 2018; Ogbolu et al., 2018). Time and work pressure in daily care provision is high and, in these circumstances, the demand for person-centred care cannot be seen as a realistic policy requirement. The structural barriers, such as difficult cooperation and austerity measures, can be seen as an additional barrier in the provision of care to persons with a migrant background, but these structural barriers also reinforce the other perceived barriers (Bagnasco et al., 2018).

Within the healthcare system, it is in certain situations possible for individual healthcare professionals to spend more time on the individual needs of the patient. However, this choice has negative financial consequences for the healthcare provider. Moreover, this remains an individual choice, and there is no structural policy on this matter from the healthcare organization. The individual choice to spend more time in providing quality of care does not fit into the healthcare system, which is based on rewarding care provision within a limited time frame.

As in any research, certain limitations can be identified in this study. Firstly, it could be stated that the participants of this study had rather similar opinions and experiences in relation to the research question. Second, a selection bias may have occurred, as all participants participated voluntarily in this study. As a consequence, this can cause an over-representation of participants with an interest in this topic of ethnic diversity in care and an under-representation of participants not interested in the topic. Finally, the sample of participants included a combination of students and professionals, which may lead to under-representation of certain healthcare professionals regarding the topic.

4.5 Conclusion

Healthcare professionals experience a number of barriers while providing care for patients with a migration background. However, only a limited number of facilitators were acknowledged. As indicated above, ‘othering’ appears to play a crucial role in the identification of several of these barriers, and in building or maintaining several barriers. In addition, other factors also play a role, such as awareness, skills and attitudes. We can conclude that a multilevel and a multifactor approach is necessary to tackle the barriers identified regarding providing quality care to patients with a migration background. A multilevel approach should address the barriers at the level of the healthcare provider, the management, and the healthcare system. At the same time, efforts should be made to focus on multiple factors, such as awareness of othering, recognition and appreciation of the competences of the care providers and tackling discrimination and racism in care.

4.5.1 Relevance to clinical practice

Taking into account the above identified barriers, ‘othering’ plays an important role in the construction and maintenance of those. We suggest that a multilevel approach is necessary to tackle the very present ‘othering’ within care provision. Other barriers at healthcare provider, managerial, and healthcare system levels should be tackled too.

A formal acknowledgement of the essential competencies for healthcare professionals in looking after patients with a migration background, and enhancing a multi-lingual healthcare environment, seem essential in this context (Hughson et al., 2018; Martin-Matthews et al., 2010).

Finally, mandatory training on cultural diversity should be integrated in all healthcare professionals’ curricula, with no delay (HyeRin Roh & Nirta, 2018). Moreover, mandatory training and continuous support of all healthcare professionals on cultural competences seems essential.

References

Antunes, V., & Moreira, J. P. (2011). Approaches to developing integrated care in Europe: A systematic literature review. *Journal of Management & Marketing in Healthcare*, *4*(2), 129–135. https://doi.org/10.1179/175330311X13016677137743

Arnaut, K., Blommaert, J., Rampton, B., & Spotti, M. (2015). *Language and Superdiversity*. Routledge.

Aspinall, C., Jacobs, S., & Frey, R. (2021). The impact of intersectionality on nursing leadership, empowerment and culture: A case study exploring nurses and managers' perceptions in an acute care hospital in Aotearoa, New Zealand. *Journal of clinical nursing*. https://doi.org/10.1111/jocn.15745

Bagnasco, A., Timmins, F., Aleo, G., & Sasso, L. (2018). Double Jeopardy – Missed care for the vulnerable in community settings. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *27*(21–22), 3827–3829. https://doi.org/10.1111/jocn.14541

Barrett, B., Shadick, K., Schilling, R., Spencer, L., del Rosario, S., Moua, K., & Vang, M. (1998). Hmong/medicine interactions: Improving cross-cultural health care. *Family Medicine*, *30*(3), 179–184.

Beck, C. T., & Polit, D. F. (2014a). *Essentials of nursing research. Appraising evidence for nursing practice* (Campus Jette - GEZ 613.2; 8e ed.). Wolters Kluwer.

Beck, C. T., & Polit, D. F. (2014b). *Essentials of nursing research. Appraising evidence for nursing practice* (Campus Jette - GEZ 613.2; 8e ed.). Wolters Kluwer.

Bengtsson, M. (2016). How to plan and perform a qualitative study using content analysis. *NursingPlus Open*, *2*, 8–14. https://doi.org/10.1016/j.npls.2016.01.001

Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*, *101*, 103413. https://doi.org/10.1016/j.ijnurstu.2019.103413

Berdai Chaouni, S. (2021). *Grasping Fading Memories of a Motherland: Capturing Dynamic Care Realities of Older Labor Migrants with Dementia.* [PhD Thesis].

Berg, K., McLane, P., Eshkakogan, N., Mantha, J., Lee, T., Crowshoe, C., & Phillips, A. (2019). Perspectives on Indigenous cultural competency and safety in Canadian hospital emergency departments: A scoping review. *International Emergency Nursing*, *43*, 133–140. https://doi.org/10.1016/j.ienj.2019.01.004

Bernard, H. R., & Bernard, D. H. R. (2000). *Social Research Methods: Qualitative and Quantitative Approaches*. SAGE.

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal*, *204*(8), 429–432. https://doi.org/10.1038/sj.bdj.2008.292

Carlsson, H., & Pijpers, R. (2020). Working towards health equity for ethnic minority elders: Spanning the boundaries of neighbourhood governance. *Journal of Health Organization and Management*, *35*(2), 212–228. https://doi.org/10.1108/JHOM-08-2020-0325

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2020). Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals. *Journal of Transcultural Nursing*, 1043659620970625. https://doi.org/10.1177/1043659620970625

Cyril, S., Nicholson, J. M., Agho, K., Polonsky, M., & Renzaho, A. M. (2017). Barriers and facilitators to childhood obesity prevention among culturally and linguistically diverse (CALD) communities in Victoria, Australia. *Australian & New Zealand Journal of Public Health*, *41*(3), 287–293. https://doi.org/10.1111/1753-6405.12648

Dell'aversana, G., & Bruno, A. (2021). Supporting Cultural Competence: Practices of Managers and Line Workers in a Health Service. *TPM: Testing, Psychometrics, Methodology in Applied Psychology*, *28*(1), 65–81. https://doi.org/10.4473/TPM28.1.5

Dervin, F. (2016). Discourses of Othering. In F. Dervin (Red.), *Interculturality in Education: A Theoretical and Methodological Toolbox* (pp. 43–55). Palgrave Macmillan UK. https://doi.org/10.1057/978-1-137-54544-2_4

DiAngelo, R. (2011). White Fragility. *The International Journal of Critical Pedagogy*, *3*(3), Article 3. http://libjournal.uncg.edu/ijcp/article/view/249

Fadil, N. (2019). The Anthropology of Islam in Europe: A Double Epistemological Impasse. *Annual Review of Anthropology*, *48*(1), 117–132. https://doi.org/10.1146/annurev-anthro-102218-011353

Fatahi, N., & Krupic, F. (2016). Factors Beyond the Language Barrier in Providing Health Care to Immigrant Patients. *Medical Archives (Sarajevo, Bosnia And Herzegovina)*, *70*(1), 61–65. https://doi.org/10.5455/medarh.2016.70.61-65

Fleras, A. (2016). Theorizing Micro-aggressions as Racism 3.0: Shifting the Discourse. *Canadian Ethnic Studies*, *48*(2), 1–19. https://doi.org/10.1353/ces.2016.0011

Fret, B., De Donder, L., Lambotte, D., Dury, S., Van der Elst, M., De Witte, N., Switsers, L., Hoens, S., Van Regenmortel, S., & Verté, D. (2019). Access to care of frail community-dwelling older adults in Belgium: A qualitative study. *Primary Health Care Research & Development*, *20*. https://doi.org/10.1017/S1463423619000100

Goodwin, N. (2016). Understanding Integrated Care. *International Journal of Integrated Care*, *16*(4). https://doi.org/10.5334/ijic.2530

Grandpierre V., Milloy V., Sikora L., Fitzpatrick E., Thomas R., & Potter B.. (2018). Barriers and facilitators to cultural competence in rehabilitation services: A scoping review. *BMC Health Services Research*, *18*(1), 1–14. https://doi.org/10.1186/s12913-017-2811-1

Harrison, R., Walton, M., Chitkara, U., Manias, E., Chauhan, A., Latanik, M., & Leone, D. (2020). Beyond translation: Engaging with culturally and linguistically diverse consumers. *Health expectations : an international journal of public participation in health care and health policy*, *23*(1), 159–168. https://doi.org/10.1111/hex.12984

Hughson, J., Marshall, F., Daly, J. O., Woodward-Kron, R., Hajek, J., & Story, D. (2018). Health professionals' views on health literacy issues for culturally and linguistically diverse women in maternity care: Barriers, enablers and the need for an integrated approach. *Australian Health Review*, *42*(1), 10–20. https://doi.org/10.1071/AH17067

HyeRin Roh, & Nirta, L. (2018). Medical students interact with multicultural patients to learn cultural diversity. *Korean Journal of Medical Education*, *30*(2), 161–166. https://doi.org/10.3946/kjme.2018.91

Jones E., Lattof S.R., & Coast E. (2017). Interventions to provide culturally-appropriate maternity care services: Factors affecting implementation. *BMC Pregnancy and Childbirth*, *17*(1), 1–10. https://doi.org/10.1186/s12884-017-1449-7

Kynoe, N. M., Fugelseth, D., & Hanssen, I. (2020). When a common language is missing: Nurse–mother communication in the NICU. A qualitative study. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *29*(13/14), 2221–2230.

Markey, K., Tilki, M., & Taylor, G. (2012). Strategies to surmount the potential barriers to providing anti-discriminatory care in Irish healthcare settings. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, *40*(2), 269–276. https://doi.org/10.5172/conu.2012.40.2.269

Markey, K., Tilki, M., & Taylor, G. (2018). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *27*(1–2), e259–e268. https://doi.org/10.1111/jocn.13926

Martin-Matthews, A., Sims-Gould, J., & Naslund, J. (2010). Ethno-cultural diversity in home care work in Canada: Issues confronted, strategies employed. *International Journal of Ageing & Later Life*, *5*(2), 77.

McClimens, A., Brewster, J., & Lewis, R. (2014). Recognising and respecting patients' cultural diversity. *Nursing Standard (Royal College Of Nursing (Great Britain): 1987)*, *28*(28), 45–52. https://doi.org/10.7748/ns2014.03.28.28.45.e8148

Nair, L., & Adetayo, O. A. (2019). Cultural Competence and Ethnic Diversity in Healthcare. *Plastic And Reconstructive Surgery. Global Open*, *7*(5), e2219–e2219. https://doi.org/10.1097/GOX.0000000000002219

Narayanasamy, A. (2003). Transcultural nursing: How do nurses respond to cultural needs? *British Journal of Nursing*, *12*(3), 185–194. https://doi.org/10.12968/bjon.2003.12.3.185

Nielsen, S. S., & Krasnik, A. (2010). Poorer self-perceived health among migrants and ethnic minorities versus the majority population in Europe: A systematic review. *International Journal of Public Health*, *55*(5), 357–371. https://doi.org/10.1007/s00038-010-0145-4

Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2019). Barriers to post-diagnostic care and support in minority ethnic communities: A survey of Danish primary care dementia coordinators. *Dementia (London, England)*, 1471301219853945–1471301219853945. https://doi.org/10.1177/1471301219853945

Ogbolu, Y., Scrandis, D. A., & Fitzpatrick, G. (2018). Barriers and facilitators of care for diverse patients: Nurse leader perspectives and nurse manager implications. *Journal Of Nursing Management*, *26*(1), 3–10. https://doi.org/10.1111/jonm.12498

Piacentini, T., O'Donnell, C., Phipps, A., Jackson, I., & Stack, N. (2019). Moving beyond the 'language problem': Developing an understanding of the intersections of health, language and immigration status in interpreter-mediated health encounters. *Language and Intercultural Communication*, *19*(3), 256–271. https://doi.org/10.1080/14708477.2018.1486409

Rosenow, E. C. (2005). Patients' Understanding of and Compliance With Medications: The Sixth Vital Sign? *Mayo Clinic Proceedings*, *80*(8), 983–987. https://doi.org/10.4065/80.8.983

Ryan, A. A., & Scullion, H. F. (2000). Nursing home placement: An exploration of the experiences of family carers. *Journal of Advanced Nursing*, *32*(5), 1187–1195. https://doi.org/10.1046/j.1365-2648.2000.01589.x

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality & Quantity*, *52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Scheppers, E., van Dongen, E., Dekker, J., Geertzen, J., & Dekker, J. (2006). Potential barriers to the use of health services among ethnic minorities: A review. *Family Practice*, *23*(3), 325–348. https://doi.org/10.1093/fampra/cmi113

Seeleman, C., Hermans, J., Lamkaddem, M., Suurmond, J., Stronks, K., & Essink-Bot, M.-L. (2014). A students' survey of cultural competence as a basis for identifying gaps in the medical curriculum. *BMC Medical Education*, *14*, 216–216. https://doi.org/10.1186/1472-6920-14-216

Seeleman C, Suurmond J, & Stronks K. (2009). Cultural competence: A conceptual framework for teaching and learning. *Medical Education*, *43*(3), 229–237. https://doi.org/10.1111/j.1365-2923.2008.03269.x

Small, J., Chan, S. M., Drance, E., Globerman, J., Hulko, W., O'Connor, D., Perry, J., Stern, L., & Ho, L. (2015). Verbal and nonverbal indicators of quality of communication between care staff and residents in ethnoculturally and linguistically diverse long-term care settings. *Journal of Cross-Cultural Gerontology*, *30*(3), 285–304. https://doi.org/10.1007/s10823-015-9269-6

Smith, G. D., Chaturvedi, N., Harding, S., Nazroo, J., & Williams, R. (2000). Ethnic inequalities in health: A review of UK epidemiological evidence. *Critical Public Health*, *10*(4), 375–408. https://doi.org/10.1080/09581590010005331

Suurmond, J., Rosenmöller, D. L., El Mesbahi, H., Lamkaddem, M., & Essink-Bot, M.-L. (2016). Barriers in access to home care services among ethnic minority and Dutch elderly—A qualitative study. *International Journal of Nursing Studies*, *54*, 23–35. https://doi.org/10.1016/j.ijnurstu.2015.02.014

Taylor, R. A., & Alfred, M. V. (2010). Nurses' Perceptions of the Organizational Supports Needed for the Delivery of Culturally Competent Care. *Western Journal of Nursing Research*, *32*(5), 591–609. https://doi.org/10.1177/0193945909354999

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Torres, S. (2006). Elderly Immigrants in Sweden: 'Otherness' Under Construction. *Journal of Ethnic & Migration Studies*, *32*(8), 1341–1358. https://doi.org/10.1080/13691830600928730

Tortumluoglu, G., Okanli, A., Ozyazicioglu, N., & Akyil, R. (2006). Defining cultural diversities experienced in patient care by nursing students in eastern Turkey. *Nurse Education Today*, *26*(2), 169–175. https://doi.org/10.1016/j.nedt.2005.08.008

Uiters, E., Devillé, W. L. J. M., Foets, M., & Groenewegen, P. P. (2006). Use of health care services by ethnic minorities in The Netherlands: Do patterns differ? *European Journal of Public Health*, *16*(4), 388–393. https://doi.org/10.1093/eurpub/ckl040

UN. (2020). *United Nations Decade of Healthy Ageing (2021–2030)* (UN General Assembly A/RES/75/131).

Vissenberg, R., Uysal, O., Goudsmit, M., Campen, J. van, & Es, B. B. (2018). Barriers in providing primary care for immigrant patients with dementia: GPs' perspectives. *BJGP Open*, *2*(4). https://doi.org/10.3399/bjgpopen18X101610

Weber, R. P. (1990). *Basic Content Analysis*. SAGE.

Weech-Maldonado, R., Dreachslin, J. L., Epané, J. P., Gail, J., Gupta, S., & Wainio, J. A. (2018). Hospital cultural competency as a systematic organizational intervention: Key findings from the national center for healthcare leadership diversity demonstration project. *Health Care Management Review*, *43*(1), 30–41. https://doi.org/10.1097/HMR.0000000000000128

Wickramage, K., Vearey, J., Zwi, A. B., Robinson, C., & Knipper, M. (2018). Migration and health: A global public health research priority. *BMC Public Health*, *18*. https://doi.org/10.1186/s12889-018-5932-5

Intermezzo: The U-turn

Reflections on the unpublished paper: "The validation and refinement of the Dutch version of the Cultural Competence Assessment Instrument"

The initial intention of this PhD was to start with conducting two qualitative studies: the first on the perception and the second on the implementation of culturally sensitive care among healthcare providers. Based on these, the plan was to adapt and validate an assessment instrument for measuring cultural competence as the third study, and to use this instrument to measure the cultural competences of healthcare providers as the fourth study. I had come a long way and spent several years of my PhD on this data collection, analysis and writing the papers. However, I stopped because I did not believe anymore in the added-value and usability of such an instrument.

The aim to measure competences as the planned third study.

Starting from the need to assess the cultural competencies of healthcare providers, the aim of this study was to adapt and validate the Cultural Competence Assessment Instrument (CCAI) for Belgian Dutch-speaking healthcare providers (Doorenbos et al., 2005; Schim et al., 2007). Although several instruments have been developed and adapted to assess cultural competence across different disciplines and settings in healthcare, no translated and validated instrument is available in Dutch for the Belgian context.

The theoretical background of CCAI is the Cultural Competence Model by Doorenbos and Schim, which encompasses four key elements (Schim et al., 2007):

- Cultural diversity refers to the recognition that diversity is a fact in the current healthcare setting and that it is a complex and dynamic reality.
- Cultural awareness refers to one's knowledge of differences and similarities in cultural expression, and an understanding that these differences influence interactions between individuals.
- Cultural sensitivity refers to one's attitudes, beliefs, and representations about the characteristics of others.
- Cultural competence behaviour is the behaviour of the healthcare provider, which depends on their cultural diversity, awareness, and sensitivity.

The process of validation and refinement

In the process of the validation and refinement of the assessment instrument, different stages were completed:

First, an explorative literature review was conducted to select an instrument that measures the cultural competencies of health care providers. The criteria for selecting the cultural competence assessment instrument were: (1) it must be based on a theoretical model of cultural competence, (2) it must be applicable to an interdisciplinary health care team, and (3) it must be accessible to various groups (discipline, educational level, culture, gender). The

Cultural Competence Assessment Instrument (CCAI) was chosen because (1) it is based on the model of Culturally Congruent Care (Schim et al., 2007a), (2) it can be used across different disciplines, and (3) it is easy to use with diverse groups and in various settings, such as acute care, primary care, or chronic care (Schim et al., 2003).

Second, the CCAI was translated by two researchers independently. Two Dutch forward translations were made of the 26 items of the CCAI by these independent researchers. Subsequently, the two translated versions of the instrument were compared, and the best expressions were selected by consensus.

Third, an expert panel reviewed the appropriateness and completeness of the 26 items of the instrument for the Belgian context. The expert panel consisted of seven individuals (four female, three male) working in the field of health care as researchers, intermediary professionals, or lecturers. To evaluate the content and face validity, the expert panel conducted two rounds of review. In the first round, they assessed the conceptual and linguistic levels, as well as the appropriateness and accessibility. In the second round, they evaluated the division of the sub-scales in the translated version of the CCAI. Based on feedback from the expert panel, three questions were added concerning the respondent's perception of culture, culturally competent care, and culturally competent health care providers.

Fourth, input was gathered from a multidisciplinary group of healthcare providers. This group included eight nurses, two physicians, and two midwives who reviewed the 26 items of the instrument, along with the three additional questions added after the first round with the expert panel. These three questions were evaluated with the multidisciplinary group and were described as clear and understandable. The group evaluated the appropriateness of the instrument for different care settings and its accessibility for various disciplines.

Fifth, a pilot study was conducted among 152 nursing students in a digital format. The aim was to assess the scale and evaluate its completeness, accessibility, and suitability for the setting. The selected students all had internship experience as nursing students in the diverse city of Brussels. Exclusion criteria were non-Dutch speaking students and students who have not gained working experience. The students received a link to an online questionnaire, which included an initial page informing them that participation was voluntary and anonymous, that they could quit the questionnaire at any time, and that their data would be used for research purposes. The factor structure was examined using exploratory factor analysis derived from principal component analysis. The 29 items of the instrument were divided into four dimensions: cultural awareness, cultural knowledge, cultural sensitivity, and cultural skills. Internal consistency was assessed using Cronbach's alpha coefficients. For each item of the instrument, the “Cronbach’s Alpha if the item was deleted” was compared to the feedback from the expert panel, multidisciplinary group, and pilot study. Based on this analysis, three items were removed from the questionnaire. They were replaced with two comparable items derived from the additional questions. Confirmatory factor analysis was used to confirm the scale, the 4 sub-scales and the items. Based on this analysis, additional items were deleted, resulting in 16 items being confirmed by the confirmatory factor analysis.

Doubt and hesitation.

Conducting this study, immersing myself in the theme of culturally sensitive care, and working on the Diverse Elderly Care project all increased my self-awareness and self-reflection to a large extent. At a certain point, while writing the paper on this study, I realized that my research aim could not be achieved. I was writing about a self-reported questionnaire designed to measure, among other things, the awareness and sensitivity of healthcare providers and student healthcare providers. My own increased awareness led me to understand that the questionnaire's design would miss its target. A self-reported questionnaire cannot accurately measure cultural awareness if the healthcare provider lacks self-awareness and critical reflection regarding their own position towards culturally sensitive care. This healthcare provider might even receive a high score on the test, but this would be based on the very lack of self-awareness. The problem was the self-reported nature of the questionnaire, combined with the measurement of self-awareness. I needed to acknowledge the limitations of self-reported measures in this context.

The U-turn

Despite having conducted the analysis and written the draft of this paper, I could not proceed with publishing it. I discussed my concerns with my promoter and advisory committee. Fortunately, they understood my hesitations about the purpose of the questionnaire, and we all agreed to prioritize research integrity over output productivity. At this point, I made a U-turn, returning to qualitative research with a focus on highlighting the perspective of informal carers and developing an educational module. In the meantime, the research on the questionnaire has been shelved, and my paper on this research will not be published.

Conclusion

If the health professionals lack self-awareness and self-reflexivity on their own cultural competence, the questionnaire may produce distorted results, incorrectly demonstrating that the healthcare provider has cultural awareness and sensitivity.

References

Doorenbos AZ, Schim SM, Benkert R, & Borse NN. (2005). Psychometric evaluation of the cultural competence assessment instrument among healthcare providers. *Nursing Research*, *54*(5), 324-331.

Schim SM, Doorenbos A, Benkert R, & Miller J. (2007). Culturally congruent care: Putting the puzzle together. *Journal of Transcultural Nursing*, *18*(2), Article 2.

Schim SM, Doorenbos AZ, Miller J, & Benkert R. (2003). Development of a cultural competence assessment instrument. *Journal of Nursing Measurement*, *11*(1), 29-40.

Chapter 5: Bridging the gaps: narratives of informal carers of older migrants with dementia on professional care.

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Submitted to Ageing and Society

Abstract

With society's growing ethnic and cultural diversity, it is increasingly crucial to comprehend the care needs of older migrants with dementia and their informal carers. This study explores the experiences of informal carers of older migrants with dementia using professional care to determine whether the delivered professional care matches the needs of both the informal carer and their family member with dementia.

Seventeen informal carers, living in Belgium and caring for older first-generation labour migrants from Italian and Turkish backgrounds, were identified through purposive sampling. In-depth interviews were conducted, and inductive data analysis was employed using the Qualitative Analysis Guide of Leuven (QUAGOL), a method inspired by the constant comparative method. Composite narrative vignettes were utilized to present the findings.

Analysis of the data revealed six predominant themes: (1) Informal carers are hoping for engagement from the professional care providers in order to create together a care alliance for the older person with dementia; (2) Informal carers experience cold sub-standard care provision from professional care providers towards their loved ones; (3) Informal carers need to feel a sense of home in order to be able to trust the professional care providers; (4) Informal carers experience culturally insensitive care practices by professional care providers; (5) Informal carers struggle with the responsibility of informal caregiving in the context of today's world; (6) Informal carers experience the cumulative mental load of caregiving.

Informal carers of older migrants with dementia face a cumulative mental burden due to various factors such as limited adapted care options, cultural insensitivity in services, caregiving duties, and additional tasks to bridge the gaps in professional care. While some interactions with professional care are positive, they are occasional rather than structural.

Keywords

Composite vignettes, culturally sensitive care, dementia care, healthcare, informal carers, older migrants, professional healthcare provider, qualitative analysis.

5.1 Introduction

With the global population ageing, dementia is becoming more prevalent, increasing demands on healthcare systems worldwide (WHO, 2024). Older persons with dementia require careful, dedicated long-term care, which is often initially provided by informal carers (Ahmad et al., 2020). As the condition progresses, formal care becomes increasingly integrated in the total care provision, challenging ageing societies where care systems often depend on ageing family members to bridge the gap between needs and formal services (Duran-Kiraç et al., 2022; Nielsen et al., 2021; Vangen & Herlofson, 2023).
As Western society is becoming increasingly diverse in terms of ethnicity and cultural background (Brussels Studies Institute, 2022), this diversity is also present among older adults and persons with dementia, and it impacts the way care is, or should be, structured and provided (Nielsen et al., 2011, 2019). In the Belgian context as well, which mirrors these demographic trends, the provision of dementia care for the country's diverse population, including older labour migrants, presents unique challenges and opportunities in dementia care delivery (Berdai Chaouni, 2021). In 1946, Belgium and Italy agreed that Italy would send guest workers to Belgian mines in exchange for coal (Morelli, 1988). Labour migrants arriving in Western Europe from the 1950s to the 1970s worked in low-wage, manual labour jobs with limited upward mobility, facing language barriers, socio-economic challenges and exclusion related to their status as labour migrants. After a 1956 mining disaster ended the agreement with Italy, Belgium established new bilateral agreements, including one with Turkey in 1964. Today, Italian and Turkish communities remain present in Belgium, with many of the first-generation migrant workers now older persons. The migration history impacts their current disadvantaged socioeconomic position (Berdai Chaouni, 2021; Morelli, 1988).

Culturally sensitive care is frequently promoted as a way to provide appropriate care for persons of diverse ethnic and cultural backgrounds (Sagar, 2012; Shen, 2015). A culturally sensitive care approach is used when patient and health care professional - from different ethnic–cultural backgrounds - are in interaction with each other to search for a connection in order to build a (better quality) care relationship (Uzun & Sevinç, 2015). This care relationship is affected by the cultural characteristics of both the patient and the health care professional. By accepting and overcoming these cultural differences, a customized concept of care begins. The latter responds to the questions and needs of the patient, regardless of their culture, religion, or origin (Claeys et al., 2020). However, in the context of care, it remains unclear how informal carers of older migrants experience the cultural sensitivity of the professional care they receive. Recent studies underline a discrepancy between professional care providers' interpretations of culturally sensitive care and the actual experiences of older adults – several studies highlight the unmet needs of persons with a migration background and their informal carers (Ospina-Caicedo et al., 2022; Tee et al., 2022; White et al., 2019), and other studies emphasize the difficult perception and implementation of culturally sensitive care by healthcare professionals (Claeys et al., 2020, 2022). The literature indicates a misalignment between the professional care provided and the actual needs and preferences of older adults and their informal carers (Berdai Chaouni et al., 2020). This can result in culturally insensitive care – neglecting the patients' cultural backgrounds, preferences, and needs – resulting in inadequate and sometimes harmful experiences (Almutairi et al., 2017; Markey et al., 2019; Qureshi, 2020). Although more and more research is available, there is still little empirical literature that makes a clear connection between culturally insensitive care and implicit and explicit racial micro-aggressions in healthcare (Miller & Peck, 2020; Moorley et al., 2020; Moorley & West, 2022; Snyder et al., 2018). Microaggressions can be defined as deniable acts of racism that reinforce harmful stereotypes and hierarchies. The concept marks an evolution in understanding bias, as these actions are subtle, often covert in casual conversation, rather than overt.

Microaggressions are often unconsciously and are only noticed by persons aware of gender or racial stereotypes in that context. They are cumulative, daily occurrences that result in psychological and physical trauma (Salmon, 2024). Further research is needed to clarify this. However, this paper will focus on the aim to better understand the experiences of informal carers with the professional care for the older migrant with dementia by investigating whether the care provided aligns with the needs of both the informal carer and their family member.

5.1.1 Literature review

Older adults and informal carers with a migration background often invest a lot of effort and work to gain access to formal healthcare services. Scientific research highlights the various challenges faced by informal carers with a migration background in their interactions with professional care (Stenberg & Hjelm, 2023), including: barriers in (1) accessing and (2) using formal services and (3) the informal carer's inter- and intra-personal barriers.

First of all, barriers in accessing formal services include: a lack of information on formal services (Wangler & Jansky, 2021), understanding and awareness of the offer of formal services (Parveen et al., 2018), coupled with a general lack of adapted services for persons with a migration background (Herat-Gunaratne et al., 2020; Sagbakken, Spilker, & Nielsen, 2018). Professional care providers are less likely to provide information to informal carers with a migration background (Wangler & Jansky, 2021) and are less likely to make referrals to professional services (Duran-Kiraç et al., 2023; Mukadam et al., 2011). Consequently, informal carers have less interaction with formal services as well as less knowledge of the existence of these services and what they offer (Nielsen et al., 2021; Parveen et al., 2018). Moreover, there is an absence of healthcare organizations specifically tailored to the needs of older migrants (Berdai Chaouni et al., 2020; Herat-Gunaratne et al., 2020; Sagbakken, Spilker, & Nielsen, 2018). However, research has shown that minority-specific services could facilitate access to healthcare in general, not only for the specific minority they are targeted towards. Minority-specific services can be seen as a gateway to a broader range of formal care services (Carlsson, 2023).

Second, when informal carers do access professional care services, they often face barriers related to the use of the care services and the care delivery. The quality of the care expected by informal carers does not always correspond with the actual care delivered (Blix & Munkejord, 2022). Quality concerns and distrust arise from inexperienced professional care providers, who lack competencies to work with older persons with dementia with a migration background and their informal carers. (Duran-Kiraç et al., 2022; Stenberg & Hjelm, 2023). Language and communication barriers exacerbate the challenges faced by individuals with a migration background in using healthcare services (e.g. lack of a shared language between the older adult and healthcare provider, the informal carer's concern that limited use of the mother tongue may impact dementia progression, hindered communication with services due to language differences starting from information about services to service provision itself) (Blix & Munkejord, 2022; Greenwood et al., 2015). Other challenges in care utilization include encounters with professional care providers lacking experience in person-centred care (Sagbakken, Spilker, & Nielsen, 2018), a lack of continuity of care (Duran-Kiraç et al., 2022), and insufficient consideration of the individual needs of the older migrant – resulting in culturally insensitive care (Herat-Gunaratne et al., 2020). Behaviours experienced as discrimination and othering lead to distrust in both the informal carer and the person in need of care (Alpers, 2018; Zemouri et al., 2024).

In the specific context of Belgium, informal carers must navigate a complex and often non-transparent healthcare and service delivery landscape, in which it is not always clear which services to approach for certain needs, and what compensatory aids or support they can rely on (De Lepeleire, 2022). Such barriers contribute to the complexities inherent in informal carers accessing and using formal care. As in other countries – such as those operating under quasi-market systems and where deinstitutionalisation of care takes place – informal carers may encounter similar challenges in understanding, accessing and using available care services and support mechanisms (Egdell, 2013).

Third, other challenges contribute to inter- and intra-personal barriers experienced by the informal carer when using formal services. Among other things, the experience of the informal caregiving depends on the nature of the relationship, the circumstances in which care is provided, and whose choice it is (Palacios et al., 2022). Research has identified that barriers often revolve around expectations placed upon the informal carer, which originate from the older person, their surrounding network, or self-imposed expectations by the informal carer (Herat-Gunaratne et al., 2020; Mazaheri et al., 2011; Shrestha et al., 2023). These expectations are commonly characterized by the terms 'duty of care' and 'filial responsibility' (Ahmad et al., 2020; Herat-Gunaratne et al., 2020; Sagbakken, Spilker, & Ingebretsen, 2018). Further, informal carers encounter stigma, inhibiting them from seeking professional care (Guan et al., 2023; Nielsen et al., 2021). This stigma may be associated with the specific condition (such as a diagnosis of dementia) or with the utilization of professional care in connection with the sense of filial responsibility (Sagbakken, Spilker, & Nielsen, 2018).

Recognizing the imperative of person-centred care, it is essential to integrate the voices of older adults and informal carers in healthcare evaluation and change management processes (Brooks et al., 2022; Fjær, 2022). Informal carers, being closest to the older person with dementia, play a crucial role in the overall care provision. By focusing on their experiences of the cultural sensitivity of professional care, the present study aims to better understand the experiences of informal carers with the professional care for the older migrant with dementia by investigating whether the care provided aligns with the needs of both the informal carer and their family member.

5.2 Methods

This study is part of the larger Diverse Elderly Care research project (funded by the European Regional Development Fund (ERDF)), which investigated culturally sensitive dementia care for older first-generation labour migrants in Brussels, Belgium. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist guided the methodological reporting (Tong et al., 2007). Ethics approval for this study was obtained from the Ethics Committee of the University Hospital of Brussels (CE 2016–105).

5.2.1 Design

This study employs a phenomenological approach to describe and understand the lived experiences of informal carers. Because the aim of the study was to describe experiences, a qualitative research method with individual in-depth interviews was chosen. The descriptive phenomenological research design aims to understand the nature of the phenomenon by exploring into the perspectives of those who have lived through it (Marshall & Rossman, 2014). By integrating the narrative approach, this study also sought to include the stories that individuals told about their experiences in the analysis (Riessman, 2008). By combining a phenomenological and narrative approach, this study worked with the strengths of both approaches, providing a more comprehensive understanding of experiences by integrating the essence of the experiences with the richness of personal stories.

5.2.2 Data collection

The (interview) participants were recruited by the first and second authors, who identified them through a network of contact persons within the local community (e.g. social worker in local community centre or local organisation, general practitioner). Participants were selected using purposive sampling, with the inclusion criterion being that they were caring for a first-generation labour migrant family member with dementia. They were invited to participate, either directly by the first or second author via telephone, where the study's aim was explained, or through the contact person who facilitated the meeting. Participants were interviewed at a time and location of their preference. Data collection took place between November 2017 and January 2019, with interviews arranged at convenient times and locations for the participants. The average duration of the interviews with the informal carers was 82 minutes, with a range of 49-123 minutes. The conducted interviews included rich and thick data.

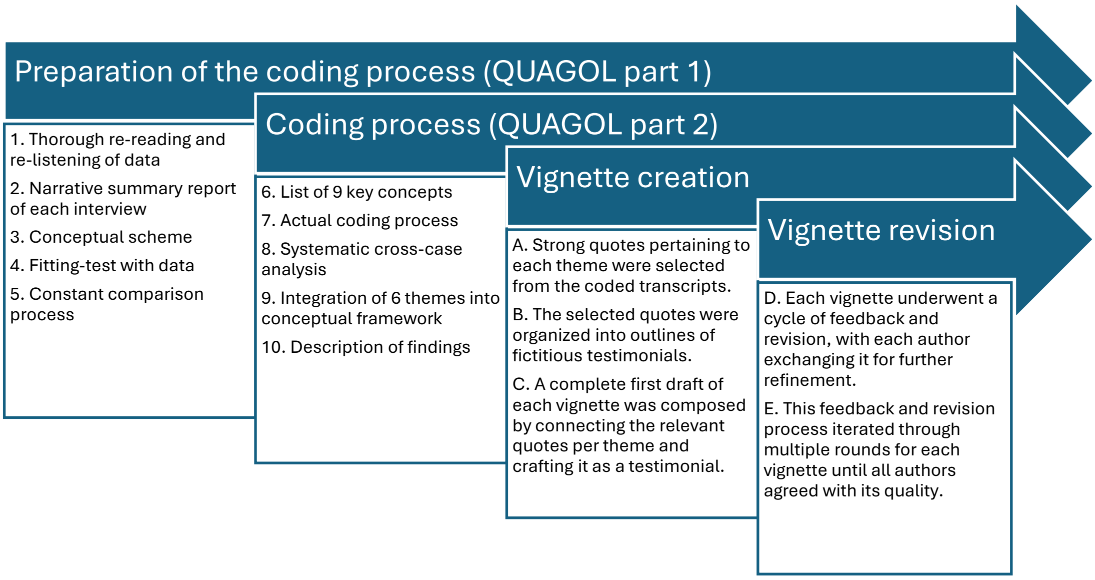
Interview guidelines, informed by a literature review, covered topics including experiences with illness trajectory and diagnosis, provision of informal care, cooperation with professional care, and identified caregiving needs. During data collection, a flexible approach was adopted that allowed the participants to discuss personally relevant issues beyond pre-determined themes. The interviews were audio-recorded and then transcribed verbatim by an official transcription service. Following each interview, debriefing reports were compiled, incorporating observational notes and process-related comments. The data collection was conducted by the first and second authors, both of whom were working as researchers on the project at the time. Throughout the research process, joint reflective exercises were undertaken by the researchers collecting the data to mitigate potential biases. Both researchers had expertise in qualitative research methods, healthcare organization, management, and culturally sensitive care.

Throughout the process, confidentiality was strictly maintained, with special attention given to ensuring data protection and GDPR compliance. Informed consent forms were provided in multiple languages, including Dutch, French, Turkish, and Italian, and explained to participants at the start of the interview to ensure they understood the content before consenting. Interviews were conducted in Dutch, French, or Turkish, with the assistance of an interpreter as needed. The participants were assured of anonymity and confidentiality, as identifiers were replaced by numerical codes in transcriptions. The researchers' contact details were provided along with the informed consent forms.

5.2.3 Data Analysis

Figure 2 gives an overview of the data analysis process. Following the qualitative method of constant comparative analysis, the data were analysed through the 10 steps of the Qualitative Analysis Guide of Leuven (QUAGOL), which consists of 2 parts: (1) the thorough preparation of the coding process, and (2) the actual coding process. Each part consists of 5 stages.

Figure 2: An overview of the data analysis process and the design of the composite vignettes.



1. Thorough re-reading and re-listening of data
2. Narrative summary report of each interview
3. Conceptual scheme
4. Fitting-test with data
5. Constant comparison process

6. List of 9 key concepts
7. Actual coding process
8. Systematic cross-case analysis
9. Integration of 6 themes into conceptual framework
10. Description of findings

A. Strong quotes pertaining to each theme were selected from the coded transcripts.

B. The selected quotes were organized into outlines of fictitious testimonials.

C. A complete first draft of each vignette was composed by connecting the relevant quotes per theme and crafting it as a testimonial.

D. Each vignette underwent a cycle of feedback and revision, with each author exchanging it for further refinement.

E. This feedback and revision process iterated through multiple rounds for each vignette until all authors agreed with its quality.

While these stages follow a sequential path, it is impossible to rigidly isolate the parts or the stages. The ongoing interaction between data collection and analysis naturally leads to merging and interaction among the parts and the stages (Dierckx de Casterlé et al., 2012, 2021). In the first part, all of the interviews underwent meticulous review, including thorough re-reading and re-listening. Subsequently, a narrative summary report was generated for each interview, incorporating contextual characteristics to contextualize the interviews. This process facilitated a deeper understanding of each interview within its specific context. During this step it became clear that the interviews from the Italian and Turkish transcripts contained similar themes and that they could be analysed together. Using a conceptual interview schedule, 9 key concepts were distilled from these narrative summary reports. This inductive list of concepts underwent validation through discussion with the co-researchers, and they were again cross-checked with the interviews. In the second part, data were coded with this list, using the qualitative data analysis software MAXQDA©. The interpretation of these concepts was guided by narrative theory, with particular attention paid to the narrative of the informal carer. The analysis of the 9 concepts took place in several iterative rounds, and the essential structure of 6 concepts were extracted as the informal carers' experiences with professional care (see Table 4 in the Appendix).

Thereafter, we created composite vignettes to present the findings. This approach allows the authors to combine common themes identified from the participants using a creative writing process, thereby crafting a more comprehensive shared story (Spalding & Phillips, 2007). Drawing upon the different steps for designing and using vignettes, and following Schinke and colleagues' approach, the 6 finalized themes from data analysis served as a framework for the composite vignettes (Schinke et al., 2016, 2017). Rather than presenting a selection of individual participant quotes in the results section, the authors constructed composite vignettes that merge the participant's experiences into more comprehensive shared and cohesive narratives (Bradbury-Jones et al., 2014; Spalding & Phillips, 2007). The vignettes incorporate both direct participant quotations and paraphrased expressions in order to provide a holistic representation of the experiences of informal carers of older persons with dementia. It is important to note that these first-person vignettes do not singularly represent any individual participant's experience, but rather offer a synthesized representation of various perspectives, fictionalizing the experience of the informal carers (Ekengren et al., 2020; Spalding & Phillips, 2007). They amalgamate multiple perspectives into fictionalized narratives. The vignettes are conceived as ‘collective stories’ that recognize the interconnectedness among informal carers (Blodgett et al., 2011; Paquette et al., 2019). The silencing of informal carers has been documented in other studies (Hengelaar et al., 2024). By using vignettes, we amplify their voices, allowing them to share their experiences in a more powerful way. This approach enables the authors to better illustrate the interactions and contexts that shape the informal carers’ experiences.

As explained, the experiences of carers with Italian and Turkish roots were analysed together, which led to the identification of the 6 themes. In constructing the vignettes, decisions were made to share experiences from the perspective of carers with Italian or Turkish backgrounds when contextually appropriate, thus underlining the shared nature of the experiences across both groups.

The data analysis was conducted by the first author, in close interaction and exchange with the other authors. All of the authors are experienced in conducting qualitative research and using data analysis, and they hold positions as lecturers in healthcare or research programs.

5.3 Results

A total of 17 individual interviews were conducted with informal carers from migrant backgrounds: the interviews comprised 12 women and 5 men, including 9 individuals with Italian backgrounds and 8 with Turkish backgrounds, as described in table 7 (in the Appendix). All cared for first-generation labour migrants. They provided help and support on a regular basis. Nine participants lived in the same household as the older adult.

The experiences of informal carers with professional care, in caring for a person with dementia, are reflected in 6 major themes. Although the findings are listed below as separate themes, it is important to emphasize that these are not isolated experiences, and that the different experiences can influence each other, in a positive or in a negative cumulative way. Each theme is first described and then presented in a collective vignette per theme.

5.3.1 Engagement to create a care alliance

Warm, empathetic relationships between professional care providers, older adults, and informal carers fostered trust, security, and support. Participants noted that these interactions, characterized by an open attitude and initiative from the care providers, built a trusting bond. For the informal carer, trust in this context means the assurance that the healthcare provider will deliver care with the same dedication as the informal carer, fostering confidence that the older person is in safe hands. Warmth is experienced as a positive connection, feeling acknowledged, and receiving empathetic attention from the healthcare provider. Care providers’ genuine concern made informal carers feel like allies in the care process, by listening attentively and giving emotional support. The open attitude from the care providers showed engagement – for example, through creative thinking to tailor the care to the individual needs of the older person. Lastly, the participants experienced an initiative-taking attitude in the care providers, through actions like arranging home care or anticipating future needs. However, the narratives of the participants showed that this level of engagement was not inherent in all professional care providers and was often hindered by systemic limitations such as inaccessible healthcare structures, time constraints, and limited staffing.

> *"It's so important for me and my mother that the people taking care of my father are truly involved. It's not just about meeting his physical needs, but also about understanding who he is as a person.*
> *Luckily, we've found a few care providers who have really built a warm relationship with him. They're really great guys. They listen to him and make him feel valued. It is so funny. They call him uncle in Turkish – even though they are not related – and that makes him feel respected. It warms my heart to see how they interact with him, how he goes to day care during the week and asks about them on weekends.*
> *My father couldn't go to day care for a while because he was in the hospital. They called us from day care to ask about him. It gives me so much peace and confidence to know they're there and that they really care about him.*
> *Of course, there are also times when things don't go so well. Like in the hospital, none of the team spoke Turkish, we dealt with nurses who didn't understand what my father needed and weren't willing to make an effort or show some dedication.*
> *But overall, I'm grateful for the involvement we've experienced. It gives me hope and confidence that, together, we can provide the best care for my father."*
>
> *(Vignette composed with extracts from interviews T1, T4, T5, T3)*

5.3.2 The experience of cold substandard care from professional care providers

The participants shared how they were confronted with professional care that was experienced as cold and inhuman, where the rules, procedures and cost-cutting measures outweighed the needs of the individual person. The participants experienced a cold attitude (as being distant, indifferent, unresponsive) from both individual healthcare providers and the policies of care organisations. The participants expected a certain standard of quality and humanity in the professional care practice. If they did not experience this – and if, on the contrary, they were confronted with sub-standard care – it was difficult to have confidence in the professional care practice and to 'transfer' the older person from informal care to formal care with a feeling of confidence and trust. For the informal carer, care is experienced as human if it is respectful and acknowledges each individual as a unique person with a unique life history and unique needs. They experienced cold sub-standard care in different healthcare settings – e.g., home care, hospitals and long-term care facilities. The participants experienced sub-standard care as a rigid, supply-side-oriented structure that was rushed and impatient and lacked attention to the specific needs of the older person with dementia. Though their needs and questions were heard, the participants felt that these were then ignored or not addressed. They reported insufficient supervision for older persons with dementia who were confused and had the tendency to run away, alongside experiences of disrespectful treatment, poor personal hygiene, inadequate staffing with inexperienced healthcare providers, and frequent provision of sedatives. The participants described their experience of cold sub-standard care as lacking quality, compassion, and respect. This led to experiences of unsafe situations and poor communication, resulting in feelings of insecurity and distrust.

> *"My mother used to scream a lot and shouted and cursed. But that's just how my mother is, I've always known her like that, I guess it's the temperament of Southern Italy from back in the days, you see? But in the hospital and later in rehabilitation, they found it abnormal, so they gave her sedatives. At the rehabilitation centre, they said my mother couldn't go home anymore. I wanted to give it a try, but my brother and the rehabilitation centre were against*

> *that. The nursing home we had chosen had a waiting list, but she had to leave the rehabilitation centre, so she was taken to another nursing home further away.*
> *During the years she stayed in the nursing home, she received a lot of sedatives for her supposedly unmanageable behaviour. Yet whenever I was there, giving her attention and speaking or singing with her in Italian, she was always calm. Because of the sedatives, I didn't recognize my mother anymore, she was drowsy, often fell, and was covered in bruises. My mother was there, with 24-hour supervision, but I was never at ease. Is that what we want for our parents? To put them in a nursing home and sedate them until we no longer have to deal with them? I protested against the sedatives, but they gave me no choice. It was 'take it or leave it'.*
> *I had a good contact with some of the carers, they were just doing what they could. In the evenings, there were only two of them for all the work. That was the case every day: far too many residents for far too few staff. Often young girls without experience, and certainly no experience with dementia. Some of them, I believe, didn't like their job. My mother sat in a wheelchair for 3 days, with the cushion and wheelchair soiled with urine, until I couldn't bear it anymore and protested vehemently.*
> *I visited her at the nursing home every day and often brought food. She even said to me: "I don't like the food here." It didn't look good either, often unrecognisably mashed with no taste. There were other things too, like eating bread for dinner, my mother was never used to that.*
> *Look, I went along with a lot of things, but I still feel guilty about how she spent her last years."*
>
> *(Vignette composed with extracts from interviews I4, I7, T4, I1, T3, I9, T7)*

5.3.3 A sense of home builds trust in care

The participants experienced that recognizing and acknowledging the life story and the specific needs of older migrants was important in creating trust and familiarity among the older migrants and their network. The participants shared that, when using professional care, familiarity in feeling a sense of home was an important aspect that built trust for both the older person with dementia and the informal carer. The participants illustrated the importance of food (i.e., offering traditional, familiar, well-prepared meals and a recognizable meal pattern), language (i.e., the ability to communicate in the native language, especially in situations where dementia has progressed and language skills have declined), and general habits and environment (i.e., recognizable furniture, habits, and religious customs). These were an essential component of quality of life and comfort for older migrants and their informal carers. It gave them a sign that the care provided respected the cultural background of the older person. When it was provided, it helped the older person with dementia feel comfortable and safe and accepting of the professional care provided. Familiarity in the professional care provider him/herself helped create a bond of trust between the older person, the informal carer, and the professional care provider.

> *"You know, for me as a carer, it's all about familiarity when it comes to getting help for my mother. Take food, for instance: it's more than just nourishment. In our family, food is the solution for every problem. It's a sense of home, of our traditions. But sometimes, the care providers don't get it. They see food as just food; but for us, it's much more.*

> *And then there's the language. It's comforting to know there's someone around who understands her when she's anxious or starts panicking in Italian. When she can express herself in her own language, she feels more at ease. And so, do I.*
> *In addition, there are the little things, like her familiar furniture and belongings. They may seem trivial, but they're part of her identity, who she is. They bring her peace in the middle of the dementia chaos.*
> *But it's not only about the physical stuff; it's also about the people around her. Like the head nurse, who happens to be my niece's mother-in-law. Knowing that created an instant connection.*
> *You know, it's frustrating sometimes. For all those years, my parents worked hard in difficult conditions in a country that wasn't their home. I believe they deserve to be treated with respect.*
> *So, yeah, familiarity matters to us. It's about creating a sense of home, of comfort, especially during the toughest times."*

(Vignette composed with extracts from I1, I5, T4, I4, T5, T8)

5.3.4 The experience of culturally insensitive professional care

Culturally insensitive care neglected the older persons' cultural backgrounds, preferences, and needs – leading to inadequate, and sometimes harmful, experiences (e.g., refusing halal meals or refusing an older Italian woman's request to avoid male nurses). This was sometimes influenced by the care providers' lack of cultural competence (e.g., care providers' unawareness of Islamic traditions washing an older Turkish man in the toilet area, not considering the fact that this is inappropriate in his religion). Additionally, the rigid, supply-side-oriented nature of the healthcare system inhibited tailored care. Care managers or providers often refused to deviate from uniform policies, or were unable to provide tailored care due to limited care options that consider the older person's background. The participants also experienced racial micro-aggressions, both implicit and explicit (e.g., limited explanations of dementia diagnoses, not being referred to further care solutions due to assumptions about self-care, and negative comments when food is brought to the hospital). As the participants' narratives showed, these issues occurred in home care, hospitals, and residential care facilities.

> *"So, being a carer for my mother, who was dealing with dementia, let me tell you, making use of the healthcare system… it felt like we were met with some kind of challenge or obstacle every step we took.*
> *After the decision to start with homecare help, we were passed around like a hot potato between about 10 different caregivers in one week, none of whom could even communicate my mother.*
> *My mother isn't religious, but she just didn't want male caregivers. We passed this on to the home care nurses, but then they said: "we won't start with that." We then searched for a private service that would actually listen to us.*
> *When my mother was in the hospital, I would drop by after work and bring food, you know, to make her feel a bit at home. The nurse in the hallway said to me: "Why do you always bring food, she gets food from us, you know?" When I visited her together with my brothers, we again received comments that there were too many of us in the room.*
> *Honestly, I always hated standing out and asking for something particular, so we usually made it work with what was available. But at my mother's insistence, or for her well-being, I sometimes did it anyway. And then it often seemed like I was asking for something impossible. Like in the residential care facility, I asked if they could bring her dinner last and*

> *put her in bed last, because she simply isn't used to eating dinner at 4pm and going to bed at 6pm. When I asked, it felt like they would have to change their entire system and put in a lot of effort to meet my request. Which wasn't actually the case at all, of course, but that's how their reaction made me feel."*
>
> *(Vignette composed with extracts from interviews T4, I5, T2, I2, I4)*

5.3.5 Struggle with the responsibility of informal caregiving in today's world

The informal carer felt a deep duty to care for their older relative, based on the consideration: 'they cared for us, now it is our turn to care for them'. The participants perceived informal caregiving as a duty motivated by tradition, religion, and migration history, carried by love and devotion.

First, the participants' search for professional care was hindered by lack of support and information. They felt a strong responsibility for their family member's care, even when delegating tasks to other family members or professional care providers. This responsibility was paired with distrust in professional healthcare due to a lack of suitable quality care. For informal carers, quality of care also encompasses expertise, experience, capability, and empathy, providing them with a sense of reliability and safety. The participants often filled gaps where professional care fell short (e.g., creating pictograms to overcome language barriers, or organizing supervision in a residential care facility).

Second, the participants were expected to mediate, negotiate and educate between the professional care provider, the older person, and other family members – making the bridge between everyone involved to ensure that everything was, and remained, coordinated. They experienced it as challenging to find the right tone in this mediation and communication, in combination with the overall struggles and challenges they experienced.

Third, not all of the participants could fully take on informal caregiving due to other tasks like a paid job and family obligations. They experienced caregiving as a struggle, fulfilled with love, loyalty, creativity, and sacrifices. Cultural background and traditions also played a role, often facing social pressure and judgment from both the community and the professional care providers. Decisions about residential care or end-of-life care placed a heavy burden on the informal carers, making them feel they must fight for their family member's interests.

> *"As a carer for my father, I felt the weight of the responsibility resting on my shoulders. It's a duty deeply tradition-rooted in our culture, the belief that it's our duty to look after our parents, just as they cared for us when we were young. I remember how my sister, my brother, and I came together and unanimously decided that it was our turn to care for our father. But while we were determined to take on this task, we quickly realized that the challenges were overwhelming. Balancing caregiving with a job, our own family, and other responsibilities required an enormous effort from all three of us. We searched for creative solutions: I developed a whole system with calendars and pictograms, and I would call him every few hours from my workplace. My sister made meals for several days and stored them in jars in his refrigerator and freezer. But then he would eat all his meals for that day in the morning, or he would fall, and the door would be locked from the inside so my brother couldn't get in. There was a time when our father called us several times during the night – we just didn't sleep. At a certain point, it wasn't safe for him to continue living alone. And then, as a carer, you also have the responsibility to make that decision.*

> *We decided together to have him admitted to a nursing home; we tried every other option, but there was no other choice left. It was truly a heartbreaking moment... The lack of understanding from our Turkish community only made the decision harder.*
> *We visited him every day, taking turns. Sometimes it felt like we were reaching our limits, like we didn't know how to keep it all together. But still, we did. It wasn't until after his death that I realized how much this demanded of me."*
>
> *(Vignette composed with extracts from interviews I2, T8, I4, T4, T5)*

5.3.6 The cumulative mental load of caregiving

Caring for an older family member with a chronic cognitive condition was demanding for the participants. This was compounded by the responsibility of providing 24/7 care for an older person with dementia, leading to physical and emotional exhaustion. Dedicated caregiving involved a continual mental burden, alternating between hope and disappointment, and managing frustrations when the carefully organized care solution did not turn out as hoped or when the care needs increased over the course of the dementia and the entire process started again.

In addition, they faced the cumulative stress of the added burden of professional care that either failed to meet the older person's personal needs or was experienced as cold, sub-standard, and culturally insensitive. The additional tasks of mediating, negotiating and educating added more stress.

Finally, the mental burden was compounded by the guilt of caregiving responsibilities, the weight of making difficult decisions – and facing the consequences of these decisions – leaving the participants torn between rationality and emotion, often accompanied by feelings of regret and remorse. This mental burden was further influenced by whether or not the professional care met expectations. The reality of professional caregiving sometimes fell short of the expectations, causing frustration, guilt, and regret among the participants. When expectations were met, informal carers found support and satisfaction.

> *"Powerless, as a carer, I've often felt so powerless. I want to find solutions that don't exist; I want to change things over which I have no control. It feels like a constant battle between hope and disappointment, between seeking solutions and the feeling of powerlessness when those solutions aren't found. I've tried everything, from seeking help from professionals to negotiating appropriate care, but again and again, it feels like I hit walls.*
> *Caring for my parents is a 24/7 task that takes all my energy; I feel emotionally drained. I'm alone, I constantly have to make choices, organize, negotiate. Sometimes it feels like I'm running on empty, both physically and emotionally. The guilt of responsibility weighs heavily on me, even when I know I'm doing everything I can. This is the double-edged sword of my Catholic faith, I guess. I feel guilty, but my faith also gives me the strength to keep going. So, despite all the challenges and setbacks, I continue to dedicate myself to caring for both of my parents, for as long as I can."*
>
> *(Vignette composed with extracts from interviews I2, T4, I4, T8)*

5.4 Discussion

The aim of this study was to explore the experiences of informal carers with the professional care provided to older migrants with dementia in order to discover whether this care aligns with the needs of the informal carers. The findings provide a number of insights into the experiences of informal carers for an older migrant with dementia. Although the 6 themes were discussed separately, it is important to stress that they are not separate but rather cumulative experiences.

The first and second themes demonstrate the importance of a genuine engagement on the part of the professional care in the care provision, to create together with the informal carers a care alliance for the older person with dementia, and the importance of caring encounters. While research often highlights barriers and negative experiences among older adults and carers from migrant backgrounds when accessing and using formal care – similar to the experiences of cold and sub-standard care in this study (Blix & Munkejord, 2022; Sagbakken, Spilker, & Ingebretsen, 2018; Stenberg & Hjelm, 2023) – our research also yielded positive interactions with professional care and testimonies of warm quality care by professionals. Research shows that cultural factors (e.g., a shared language) can influence the occurrence of a caring encounter that professional care providers show in their interaction with older adults (Söderman et al., 2018). A caring encounter can be reaching out to initiate connection or acknowledging the unique person, whereas an uncaring encounter can be disinterest and insensitivity towards the other (Halldorsdottir, 1996; Söderman et al., 2018). Uncaring encounters, often attributed to workload and time constraints, may reflect a disengagement strategy rooted in indifference towards the older migrant, who is perceived as ‘the other’ (Markey et al., 2019b). It is important to situate the experiences of the informal carers within the context of contemporary working conditions in the healthcare sector, given its economic constraints and staff shortages (Bridgeman et al., 2018; Cheloni & Tinker, 2019). These conditions impact how healthcare providers work, leading to mental strain, low morale, and burnout—issues that have worsened since the Covid-19 pandemic (Hines et al., 2021) but had already been observed before (Hall et al., 2016; Lyndon, 2018). Research shows that poor wellbeing and burnout among healthcare providers are linked to poor patient safety, including more medical errors (Bridgeman et al., 2018; Hall et al., 2016). These working conditions can also impact the provision of culturally sensitive care. While the role of the individual healthcare provider is often considered, the role of management and policy in supporting the healthcare provider should not be overlooked (Claeys et al., 2022).

The third and fourth themes point towards the lack of culturally diverse care options and the need for recognizing the specific needs of the older person with a migration background. Informal carers desire person-centred and high-quality care, expressing familiarity and a sense of home. Therefore, this study aligns with previous calls for more and better care approaches that acknowledge individual needs and preferences (Torres, 2015). The experienced lack of culturally diverse care options is also confirmed in other studies. Especially in the area of communication and language, more attention should be paid to the interaction of older migrants with dementia (Chejor et al., 2023; Herat-Gunaratne et al., 2020; Sagbakken, Spilker, & Ingebretsen, 2018). Informal carers expect professional care providers to acknowledge the life story (e.g., migration history) and religious customs of older migrants. If these aspects are perceived as disregarded by the care provider, a lack of trust in the professional care provider can result (Jutlla, 2015). In addition, it is important to consider cultural explanations for behaviours in older persons with dementia (e.g., loud screaming among Italian women, or cursing in Turkish men). Not taking into account that this behaviour could also be a behavioural or psychological symptom of dementia could lead to misinterpretations in caregiving, especially in care for older persons with the possible occurrence of dementia or delirium (Basic et al., 2017; Chejor et al., 2023; Sagbakken, Spilker, & Nielsen, 2018). The cultural attribution may indicate a lack of knowledge among informal carers about dementia and its symptoms, but it can also suggest internalization of cultural stereotypes, leading to a failure to recognize the actual symptoms of the condition. Lastly, it is important to point out that, for many participants in this study, the interview was the first time they were able to share their caregiving experiences. It must be understood that some had not fully processed their encounters with caregiving and professional care, which requires time for reflection to gain deeper insights. Issues related to migration and cultural background sometimes involved experiencing othering and micro-aggressions of racism, which are not always easy to put into words (Carter et al., 2017). When addressing racial trauma, the informal carers sometimes had no words, or they were not able to pinpoint what was going on or what actually happened in certain situations. And if the informal carer was indeed able to put this into words, he or she often needed a safe environment to do so (Carter et al., 2017).

Finally, the fifth and sixth themes underscore the informal carers’ sense of moral duty in caregiving in the context of the migration history of first-generation labour migrants in Belgium, who left their native country with the hope of providing a better life for future generations. This context influences the difficult balance in the experienced duty and responsibility towards the informal carer (Jutlla, 2015). Moreover, the long-standing tradition of informal caregiving faces challenges in today's modern, more individualistic, and capitalist society. With increasing pressure from individualism and smaller family units, there is a growing gap between the perceived sense of duty and the practical fulfilment of caregiving responsibilities (Sagbakken, Spilker, & Ingebretsen, 2018; Shrestha et al., 2023; ten Kate et al., 2021). In addition, the findings show how informal carers mediate between professional care, the older person, and their network by negotiating, translating (in both language and terms relevant to each person), and educating. This is an additional task for which informal carers receive little recognition and are often held accountable (Duran-Kiraç et al., 2022; Duran-Kiraç et al., 2023; Stenberg & Hjelm, 2023).

The findings have highlighted cumulative stress among informal carers with a migration background. They have undertaken 3 tasks to fill gaps in professional care – e.g., providing quality care, creating a sense of home, and mediating and educating. These tasks add to their already burdensome responsibilities. Despite their efforts, informal carers receive little recognition for these roles and are often held accountable for them. Moreover, informal carers encounter challenges such as limited access to appropriate professional care and interactions with culturally insensitive or insufficient services. Balancing between hope and disappointment – along with the continuous task of negotiating and mediating between care providers and their older family member – places a heavy mental burden on them, which is also confirmed by findings in other studies (Berdai Chaouni et al., 2020; Herat-Gunaratne et al., 2020; Stenberg & Hjelm, 2023). In addition, informal carers often encounter unmet expectations, resulting in frustration and disappointment. This burden contributes to physical and emotional stress, which often manifests in chronic health issues, both during and long after providing care. This physical and emotional stress can further intensify the mental strain on informal carers (Parveen et al., 2018; Stenberg & Hjelm, 2023; Wangler & Jansky, 2021). Finally, the burden is further compounded by the difficult decisions they must make and the accompanying feelings of guilt. International research indicates that informal carers often find themselves isolated and facing seemingly insurmountable challenges (Guan et al., 2023). All these conditions create cumulative stress, which causes a high burden.

In summary, this study shows that there is an urgent need for adapted and high-quality care for older persons with a migration background who live with dementia. Additionally, there is a strong need to support and recognize informal carers. The concept of a care alliance, discussed in the first theme, shows that cooperation and understanding are possible and can lead to positive experiences.

5.4.1 Context, strengths, and limitations of this study

This study concerns informal carers as family members of older migrants with dementia. This inclusion criterion implies that the informal carers all have a migration-related family history. With regard to the professional care providers mentioned in the informal carers' experiences, this study primarily focuses on the informal carers' perspective. It does not specifically detail whether the professional care providers themselves have a migration background. Moreover, the participants usually did not discuss or inquire about the ethnicity or migration background of the professional caregivers. When mentioned, it was typically in situations where there was a shared characteristic, such as a similar migration background.
Moreover, Koehn (2009) demonstrated that, even when healthcare providers and older persons share the same ethno-cultural background, the importance of middle-class values and the process of professional socialization may hinder the healthcare providers in critically examining the ways in which race, gender, and class intersect in the delivery of healthcare.
In addition, the researchers' profiles – particularly their ethnic-cultural backgrounds – may have influenced the data collection process: one researcher had a migration background, while the other did not. During interviews, the shared migration background between the respondent and the researcher was occasionally referenced (e.g., 'you know what I mean'). It is important to recognize that certain aspects may have been left unspoken, influenced either by the shared migration history with one researcher or the absence of such a shared history with the other. The profile of the researcher can also influence the decision whether or not to work with an interpreter to conduct the interviews. In this study, three interviews were conducted with a translator, which may have an influence on the data collection (Wallin & Ahlström, 2006).

The use of composite vignettes seemed most suitable for this study for several reasons. First of all, the intention of this study was to present the findings in a way that let the data 'speak for themselves', in order to foster awareness among readers concerning the experiences of informal carers. Second, this method offers a clear and compelling format for data representation, ensuring accessibility by a diverse readership. Lastly, it facilitates understanding of the experiences of informal carers, whereby the results can be used to address policies that provide support and intervention strategies for informal carers (Crocker et al., 2021; Knight et al., 2023). In contrast to the Paquette study, in which the composite vignettes were used to shape composite characters, this study explicitly chose not to display the vignettes in the form of created characters or fictive persons in order to avoid stereotyping the informal carers (Paquette et al., 2019).

The choice to jointly analyse the experiences of informal carers with Turkish and Italian backgrounds ensured that a shared, lived story emerged in the findings. However, this choice limited the ability to explore potential differences in experiences between the two groups of informal carers. Moreover, by not distinguishing between the types of professional care the older person received (e.g., home care, residential care) in the inclusion criteria, the findings cannot be differentiated according to the type of professional care experienced. Nonetheless, it should be noted that the focus of this study is on the experiences of the informal carer, and that the care trajectory for a person with dementia often involves different types of care throughout the chronic course of the condition.

5.5 Conclusion

In conclusion, informal carers of older migrants with dementia experience a high and cumulative burden due to a range of factors unique to their situation. In addition to universal challenges experienced by all informal carer, informal carers with a migration background encounter an extra layer of burden.

This extra layer stems from the specific needs of the older person related to the migration story or cultural background as well as barriers to accessible care, a lack of support and information, a lack of culturally tailored care options, the experiences of culturally insensitive care and racial microaggressions. Moreover, informal carers take on extra tasks and responsibilities to bridge both more general and more culture-specific gaps in professional care, such as mediating, negotiating, overcoming language barriers and educating healthcare providers. Further, informal carers experience the duty motivated by tradition, religion, and migration history.

It is important to recognise this extra layer as a cumulative burden on top of the universal challenges faced by all informal carers. This makes caring for older migrants with dementia especially challenging for informal carers from a migration background.

Although substandard professional care is often encountered, it is important to note that not all interactions with professional healthcare services are negative; some informal carers report positive experiences. However, these positive encounters tend to be occasional rather than structural.

Finally, informal carers need more support and resources to relieve their mental burden and ensure the well-being of both them and the older migrants they care for.

5.5.1 Implications for Policy and Practice

Addressing the high and cumulative burden experienced by informal carers demands policy interventions aimed at improving access to person-centred and high-quality care services. Policies could focus on expanding and enhancing professional care options tailored to the needs of older migrants with dementia. Moreover, the working conditions for healthcare providers need to be enhanced to ensure they have the capacity to deliver high-quality care. In addition, training programs for healthcare professionals could be enhanced. While it is generally the case that healthcare students receive training in communication skills and patient interactions, research shows that training in cultural competencies and culturally sensitive care remains limited and fragmented (Diaz et al., 2024). The focus and integration of these courses could be improved by incorporating development of critical self-awareness and knowledge of social exclusion mechanisms, such as racism (Diaz et al., 2024; Hamed et al., 2022). Moreover, policies should prioritize providing support services for informal carers, such as respite care and counselling, to relieve the caregiving burden and prevent further implications for their physical and mental health. It is evident that support programs for informal carers can only be successful if there is sufficient high-quality and appropriate professional care for the older person at the same time.

Furthermore, there is a need for policies that promote better communication, coordination and care alliances between informal carers, professional care providers, and older migrants with dementia – such as, for example, case managers who support informal carers in navigating the healthcare system.

References

Ahmad, M., van den Broeke, J., Saharso, S., & Tonkens, E. (2020). Persons With a Migration Background Caring for a Family Member With Dementia: Challenges to Shared Care. *The Gerontologist*, *60*(2), 340-349. https://doi.org/10.1093/geront/gnz161

Almutairi, A. F., Adlan, A. A., & Nasim, M. (2017). Perceptions of the critical cultural competence of registered nurses in Canada. *BMC Nursing*, *16*, 1-9. https://doi.org/10.1186/s12912-017-0242-2

Alpers, L.-M. (2018). Distrust and patients in intercultural healthcare: A qualitative interview study. *Nursing Ethics*, *25*(3), 313-323. https://doi.org/10.1177/0969733016652449

Berdai Chaouni, S. (2021). *Grasping Fading Memories of a Motherland: Capturing Dynamic Care Realities of Older Labor Migrants with Dementia*. [PhD Thesis].

Berdai Chaouni, S., Smetcoren, A.-S., & De Donder, L. (2020). Caring for migrant older Moroccans with dementia in Belgium as a complex and dynamic transnational network of informal and professional care: A qualitative study. *International Journal of Nursing Studies*, *101*(103413), 1-9. https://doi.org/10.1016/j.ijnurstu.2019.103413

Blix, B., & Munkejord, M.-C. (2022). Indigenous Sami Family Caregivers' Experiences With Accessing and Collaborating With Municipal Health and Care Services. *Global Qualitative Nursing Research*, *9*. https://doi.org/10.1177/23333936221123333

Blodgett, A. T., Schinke, R. J., Smith, B., Peltier, D., & Pheasant, C. (2011). In Indigenous Words: Exploring Vignettes as a Narrative Strategy for Presenting the Research Voices of Aboriginal Community Members. *Qualitative Inquiry*, *17*(6), 522-533. https://doi.org/10.1177/1077800411409885

Bradbury-Jones, C., Taylor, J., & Herber, O. R. (2014). Vignette development and administration: A framework for protecting research participants. *International Journal of Social Research Methodology*, *17*(4), 427-440. https://doi.org/10.1080/13645579.2012.750833

Bridgeman, P. J., Bridgeman, M. B., & Barone, J. (2018). Burnout syndrome among healthcare professionals. *American Journal of Health-System Pharmacy*, *75*(3), 147-152. https://doi.org/10.2146/ajhp170460

Brooks, L. A., Manias, E., & Bloomer, M. J. (2022). How do intensive care clinicians ensure culturally sensitive care for family members at the end of life? A retrospective descriptive study. *Intensive & Critical Care Nursing*, *73*, 103303. https://doi.org/10.1016/j.iccn.2022.103303

Brussels Studies Institute. (2022). *Statistische indicatoren over het Brussels Hoofdstedelijk Gewest*. https://wijkmonitoring.brussels/indicators/

Carlsson, H. (2023). Migrants' pathways to aged care: The role of local relationships of care in facilitating access for super-diverse older populations. *Ageing & Society*, *43*(7), 1502-1529. https://doi.org/10.1017/S0144686X21001240

Carter, P. L., Skiba, R., Arredondo, M. I., & Pollock, M. (2017). You Can't Fix What You Don't Look At: Acknowledging Race in Addressing Racial Discipline Disparities. *Urban Education*, *52*(2), 207-235. https://doi.org/10.1177/0042085916660350

Cheloni, S., & Tinker, A. (2019). Working with older people with dementia: Motivations and demotivations among health carers. *Working with Older People*, *23*(3), 117-126. https://doi.org/10.1108/WWOP-04-2019-0007

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2020). Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals. *Journal of Transcultural Nursing*, 1043659620970625. https://doi.org/10.1177/1043659620970625

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & Donder, L. D. (2022). Barriers and facilitators in providing care for patients with a migration background. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.16491

Crocker, B., Chard, S., & Duncan, L. (2021). Composite vignettes of challenges faced by Canadian collegiate student-athletes negotiating the demands of university life. *Psychology of Sport and Exercise*, *55*, 101937. https://doi.org/10.1016/j.psychsport.2021.101937

De Lepeleire, J. (2022). Integration of Healthcare in Belgium: Insufficient, but There Is Hope. *International Journal of Health Policy and Management*, *12*, 7179. https://doi.org/10.34172/ijhpm.2022.7179

Diaz, E., Gimeno-Feliu, L. A., Czapka, E., Suurmond, J., Razum, O., & Kumar, B. N. (2024). Capacity building in migration and health in higher education: Lessons from five European countries. *The Lancet Regional Health. Europe*, *41*, 100818. https://doi.org/10.1016/j.lanepe.2023.100818

Dierckx de Casterlé, B., De Vliegher, K., Gastmans, C., & Mertens, E. (2021). Complex Qualitative Data Analysis: Lessons Learned From the Experiences With the Qualitative Analysis Guide of Leuven. *Qualitative Health Research*, *31*(6), 1083-1093. https://doi.org/10.1177/1049732320966981

Dierckx de Casterlé, B., Gastmans, C., Bryon, E., & Denier, Y. (2012). QUAGOL: A guide for qualitative data analysis. *International Journal of Nursing Studies*, *49*(3), 360-371. https://doi.org/10.1016/j.ijnurstu.2011.09.012

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., van Hout, H., & Broese van Groenou, M. I. (2022). Accessibility of health care experienced by persons with dementia from ethnic minority groups and formal and informal caregivers: A scoping review of European literature. *Dementia (London, England)*, *21*(2), 677-700. https://doi.org/10.1177/14713012211055307

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., van Hout, H., & Broese van Groenou, M. I. (2023). Informal caregiver and nurse perceptions of access to culturally appropriate health care for ethnic minority persons with dementia: A qualitative study. *Journal of Advanced Nursing (John Wiley & Sons, Inc.)*, *79*(8), 3002-3014. https://doi.org/10.1111/jan.15687

Egdell, V. (2013). Who cares? Managing obligation and responsibility across the changing landscapes of informal dementia care. *Ageing & Society*, *33*(5), 888-907. https://doi.org/10.1017/S0144686X12000311

Ekengren, J., Stambulova, N. B., Johnson, U., Carlsson, I.-M., & Ryba, T. V. (2020). Composite vignettes of Swedish male and female professional handball players' career paths. *Sport in Society*, *23*(4), 595-612. https://doi.org/10.1080/17430437.2019.1599201

Fjær, E. L. (2022). *Inequalities in Health Care Utilization in Europe* [Doctoral thesis, NTNU]. https://ntnuopen.ntnu.no/ntnu-xmlui/handle/11250/2987785

Greenwood, N., Habibi, R., Smith, R., & Manthorpe, J. (2015). Barriers to access and minority ethnic carers' satisfaction with social care services in the community: A systematic review of qualitative and quantitative literature. *Health & Social Care in the Community*, *23*(1), 64-78. https://doi.org/10.1111/hsc.12116

Guan, Z., Poon, A. W. C., & Zwi, A. (2023). Social isolation and loneliness in family caregivers of people with severe mental illness: A scoping review. *American journal of community psychology*. https://doi.org/10.1002/ajcp.12698

Hall, L. H., Johnson, J., Watt, I., Tsipa, A., & O'Connor, D. B. (2016). Healthcare Staff Wellbeing, Burnout, and Patient Safety: A Systematic Review. *PLoS ONE*, *11*(7), e0159015. https://doi.org/10.1371/journal.pone.0159015

Hamed, S., Bradby, H., Ahlberg, B. M., & Thapar-Björkert, S. (2022). Racism in healthcare: A scoping review. *BMC Public Health*, *22*(1), 988. https://doi.org/10.1186/s12889-022-13122-y

Hengelaar, A. H., Verdonk, P., van Hartingsveldt, M., & Abma, T. (2024). A sense of injustice in care networks: An intersectional exploration of the collaboration between professionals and carers with a migration background. *Social Science & Medicine (1982)*, *356*, 117169. https://doi.org/10.1016/j.socscimed.2024.117169

Herat-Gunaratne, R., Cooper, C., Mukadam, N., Rapaport, P., Leverton, M., Higgs, P., Samus, Q., & Burton, A. (2020). "In the Bengali Vocabulary, There Is No Such Word as Care Home": Caring Experiences of UK Bangladeshi and Indian Family Carers of People Living With Dementia at Home. *The Gerontologist*, *60*(2), 331-339. https://doi.org/10.1093/geront/gnz120

Hines, S. E., Chin, K. H., Glick, D. R., & Wickwire, E. M. (2021). Trends in Moral Injury, Distress, and Resilience Factors among Healthcare Workers at the Beginning of the COVID-19 Pandemic. *International Journal of Environmental Research and Public Health*, *18*(2), Article 2. https://doi.org/10.3390/ijerph18020488

Jutlla, K. (2015). The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing & Society*, *35*(5), 1032-1054. https://doi.org/10.1017/S0144686X14000658

Knight, R. L., Mackintosh, K. A., Hudson, J., Shelley, J., Saynor, Z. L., & McNarry, M. A. (2023). Battling the unknown: Using composite vignettes to portray lived experiences of COVID-19 and long-COVID. *PLOS ONE*, *18*(4), e0284710. https://doi.org/10.1371/journal.pone.0284710

Koehn, S. (2009). Negotiating candidacy: Ethnic minority seniors' access to care. *Ageing and society*, *29*(4), 585-608. https://doi.org/10.1017/S0144686X08007952

Lyndon, A. (2018). Burnout Among Health Professionals and Its Effect on Patient Safety. *Burnout Among Health Professionals and Its Effect on Patient Safety*. https://psnet.ahrq.gov/perspective/burnout-among-health-professionals-and-its-effect-patient-safety

Markey, K., Tilki, M., & Taylor, G. (2019). Resigned indifference: An explanation of gaps in care for culturally and linguistically diverse patients'. *Journal of Nursing Management*, *27*(7), Article 7. https://doi.org/10.1111/jonm.12830

Marshall, C., & Rossman, G. B. (2014). *Designing Qualitative Research*. SAGE Publications.

Mazaheri, M., Mscn, B., Sunvisson, H., Phd, R., Nikbakht Nasrabadi, A., Bscn, N., Phd, M., Sadat, M., Bscn, M., Emami, A., & Rnt, R. (2011). Bearing witness to life narratives: Iranian immigrant experiences of having a family member with dementia. *Diversity in Health and Care*, 19-28.

Miller, L. R., & Peck, B. M. (2020). A Prospective Examination of Racial Microaggressions in the Medical Encounter. *Journal of Racial and Ethnic Health Disparities*, *7*(3), 519-527. https://doi.org/10.1007/s40615-019-00680-y

Moorley, C., Darbyshire, P., Serrant, L., Mohamed, J., Ali, P., & De Souza, R. (2020). “Dismantling structural racism: Nursing must not be caught on the wrong side of history”. *Journal of Advanced Nursing*, *76*(10), 2450-2453. https://doi.org/10.1111/jan.14469

Moorley, C., & West, R. (2022). Inclusivity in nurse education. *Evidence-Based Nursing*, *25*(3), 75-76. https://doi.org/10.1136/ebnurs-2022-103570

Morelli, A. (1988). *L’appel à la main d’oeuvre italienne pour les charbonnages et sa prise en charge à son arrivée en Belgique dans l’immédiat après-guerre*.

Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International Psychogeriatrics*, *23*(7), 1070-1077. https://doi.org/10.1017/S1041610211000214

Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2019). Barriers to post-diagnostic care and support in minority ethnic communities: A survey of Danish primary care dementia coordinators. *Dementia (London, England)*, 1471301219853945-1471301219853945. https://doi.org/10.1177/1471301219853945

Nielsen, T. R., Nielsen, D. S., & Waldemar, G. (2021). Barriers in access to dementia care in minority ethnic groups in Denmark: A qualitative study. *Aging & Mental Health*, *25*(8), 1424-1432. https://doi.org/10.1080/13607863.2020.1787336

Nielsen, T. R., Vogel, A., Phung, T. K. T., Gade, A., & Waldemar, G. (2011). Over- and under-diagnosis of dementia in ethnic minorities: A nationwide register-based study. *International Journal of Geriatric Psychiatry*, *26*(11), 1128-1135. https://doi.org/10.1002/gps.2650

Ospina-Caicedo, A., Castro Franco, E., Torres Andrade, M. V., Caicedo, J. L., Tombé Morales, M. C., & Peláez-Ballestas, I. (2022). Culturally sensitive care of Misak Indigenous patients with rheumatoid arthritis in Colombia. *Rural and Remote Health*, *22*(2), 6698. https://doi.org/10.22605/RRH6698

Palacios, J., Pérez-Cruz, P., & Webb, A. (2022). The experience of caring for an older relative in Chile: Going beyond the burden of care. *Ageing & Society*, *42*(6), 1340-1359. https://doi.org/10.1017/S0144686X20001567

Paquette, K., Trudel, P., Duarte, T., & Cundari, G. (2019). Participating in a Learner-Centered Coach Education Program: Composite Vignettes of Coaches’ and Coach Educators’ Experiences. *International Sport Coaching Journal*, *6*(3), 274-284. https://doi.org/10.1123/iscj.2018-0085

Parveen, S., Blakey, H., & Oyebode, J. R. (2018). Evaluation of a carers’ information programme culturally adapted for South Asian families. *International Journal of Geriatric Psychiatry*, *33*(2), e199-e204. https://doi.org/10.1002/gps.4768

Qureshi, S. (2020). *Cultural Sensitivity experiences of South Asian Patients in Primary Care*. University of New Brunswick.

Riessman, C. K. (2008). *Narrative Methods for the Human Sciences*. SAGE.

Sagar, P. (2012). *Transcultural Nursing Theory and Models: Application in Nursing Education, Practice, and Administration (Springer, 2012)*.

Sagbakken, M., Spilker, R. S., & Ingebretsen, R. (2018). Dementia and Migration: Family Care Patterns Merging With Public Care Services. *Qualitative Health Research*, *28*(1), 16-29. https://doi.org/10.1177/1049732317730818

Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC Health Services Research*, *18*(1), 910. https://doi.org/10.1186/s12913-018-3720-7

Salmon, U. (2024). "It's wicked hard to fight covert racism": The case of microaggressions in science research organizations. *Gender, Work & Organization*, *31*(3), 727-748. https://doi.org/10.1111/gwao.12934

Schinke, R. J., Blodgett, A. T., McGannon, K. R., & Ge, Y. (2016). Finding one's footing on foreign soil: A composite vignette of elite athlete acculturation. *Psychology of Sport and Exercise*, *25*, 36-43. https://doi.org/10.1016/j.psychsport.2016.04.001

Schinke, R. J., Blodgett, A. T., McGannon, K. R., Ge, Y., Oghene, O., & Seanor, M. (2017). Adjusting to the Receiving Country Outside the Sport Environment: A Composite Vignette of Canadian Immigrant Amateur Elite Athlete Acculturation. *Journal of Applied Sport Psychology*, *29*(3), 270-284. https://doi.org/10.1080/10413200.2016.1243593

Shen, Z. (2015). Cultural Competence Models and Cultural Competence Assessment Instruments in Nursing: A Literature Review. *Journal of Transcultural Nursing*, *26*(3), Article 3.

Shrestha, S., Arora, S., Hunter, A., & Debesay, J. (2023). Changing dynamics of caregiving: A meta-ethnography study of informal caregivers' experiences with older immigrant family members in Europe. *BMC Health Services Research*, *23*(1), 1-18. https://doi.org/10.1186/s12913-023-09023-4

Snyder, C. R., Wang, P. Z., & Truitt, A. R. (2018). Multiracial Patient Experiences With Racial Microaggressions in Health Care Settings. *Journal of Patient-Centered Research and Reviews*, *5*(3), 229-238. https://doi.org/10.17294/2330-0698.1626

Spalding, N., & Phillips, T. (2007). Exploring the Use of Vignettes: From Validity to Trustworthiness. *Qualitative health research*, *17*, 954-962. https://doi.org/10.1177/1049732307306187

Stenberg, J., & Hjelm, K. (2023). Migrant informal caregiver perceptions and experiences of caring for a family member with dementia: A systematic review and thematic synthesis. *Journal of Clinical Nursing*, *32*(9-10), 2178-2192. https://doi.org/10.1111/jocn.16390

Tee, S., Üzar-Özçetin, Y. S., & Trenoweth, S. (2022). Achieving culturally competent mental health care: A mixed-methods study drawing on the perspectives of UK nursing students. *Perspectives in Psychiatric Care*, *58*(4), 1267-1280. https://doi.org/10.1111/ppc.12926

ten Kate, R., Bilecen, B., & Steverink, N. (2021). The Role of Parent-Child Relationships and Filial Expectations in Loneliness Among Older Turkish Migrants. *Social Inclusion*, *9*(4), 291-303. https://doi.org/10.17645/si.v9i4.4508

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care: Journal of the International Society for Quality in Health Care*, *19*(6), Article 6. https://doi.org/10.1093/intqhc/mzm042

Torres, S. (2015). Expanding the gerontological imagination on ethnicity: Conceptual and theoretical perspectives. *Ageing & Society*, *35*(5), 935-960. https://doi.org/10.1017/S0144686X14001330

Vangen, H., & Herlofson, K. (2023). Why care? How filial responsibility norms and relationship quality matter for subsequent provision of care to ageing parents. *Ageing & Society*, 1-25. https://doi.org/10.1017/S0144686X23000235

Wallin, A.-M., & Ahlström, G. (2006). Cross-cultural interview studies using interpreters: Systematic literature review. *Journal of Advanced Nursing*, *55*(6), 723-735. https://doi.org/10.1111/j.1365-2648.2006.03963.x

Wangler, J., & Jansky, M. (2021). Support, needs and expectations of family caregivers regarding general practitioners – results from an online survey. *BMC Family Practice*, *22*(1), 1-12. https://doi.org/10.1186/s12875-021-01381-4

White, J., Plompen, T., Tao, L., Micallef, E., & Haines, T. (2019). What is needed in culturally competent healthcare systems? A qualitative exploration of culturally diverse patients and professional interpreters in an Australian healthcare setting. *BMC Public Health*, *19*(1), 1096. https://doi.org/10.1186/s12889-019-7378-9

WHO. (2024, maart 15). *Dementia*. https://www.who.int/news-room/fact-sheets/detail/dementia

Zemouri, C., Kassi, A. N., Oñate, W. A. de, Çoban, G., & Kissi, A. (2024). Exploring discrimination and racism in healthcare: A qualitative phenomenology study of Dutch persons with migration backgrounds. *BMJ Open*, *14*(6), e082481. https://doi.org/10.1136/bmjopen-2023-082481

Appendix:

Table 4: The essential structure of six themes as informal carers' experiences with professional care, extracted from the nine original concepts in the analysis process

Original concepts divided in nine categories	Intermediate stage	Essential structure of six final themes
Engagement (engagement gives trust)	(stayed the same category)	Informal carers are hoping for engagement from the professional care providers in order to create together a care alliance for the older person with dementia.
Cold-hearted and efficient care (Cold-hearted care with the emphasis on efficiency and economic savings, gives distrust ➔ with subcategory ‘culturally insensitive care’	(stayed the same category)	Informal carers experience cold-hearted substandard care provision from professional care providers towards their loved ones.
Familiarity (familiarity gives trust)	(two categories merged)	Informal carers need to feel a sense of home in order to be able to trust the professional care providers.
Not being seen/heard/supported (Feeling of not being heard/seen as an older migrant worker or as an older migrant)		
Culturalising	Subcategory ‘culturally insensitive care’ becomes new category, together with the category ‘culturalising’	Informal carers experience culturally insensitive care practices by professional care providers.
Filial responsibility and its implementation	(two categories merged)	Informal carers struggle with the responsibility of informal caregiving in the context of today's world.
(final) responsibility about the care provision (informal carer feels/caries the final responsibility)		
Mental load (the mental load of informal caregiving)	(two categories merged)	Informal carers experience the cumulative mental load of caregiving.
Expectations of the informal carer (met, unmet and changed expectations of informal carer)		

Table 5: Description of the participants

Interviews with informal carers of Italian (I) or Turkish (T) background	**Sex of the informal carer**	**Relationship to the older person they cared for**	**Care setting used by the older person**	**Language of the interview**
I1	F	Niece	Home care and nursing home	French
I2	M	Son	Home care and residential hospital care	Dutch
I3	F	Daughter	Home care and residential hospital care	French
I4	F	Daughter	Home care, residential hospital care, rehabilitation centre and nursing home	French
I5	M	Son	Home care and residential hospital care	Dutch
I6	F	Daughter	Home care	French
I7	F	Daughter in law	Home care	French
I8	F	Daughter	Home care, residential hospital care and rehabilitation centre	French
I9	M	Spouse	Home care and nursing home	French
T1	F	Niece	Home care, day care centre and residential hospital care	Dutch
T2	F	Daughter	Home care and residential hospital care	Dutch
T3	M	Son	Home care and residential hospital care	Dutch/Turkish (+ interpreter)
T4	F	Daughter	Home care, residential hospital care, nursing home	Dutch
T5	F	Daughter	Home care and residential hospital care	Dutch

T6	M	Son	Home care	Turkish (+ interpreter)
T7	F	Spouse	Home care and residential hospital care	Turkish (+ interpreter)
T8	F	Daughter	Home care and residential hospital care	Dutch

Chapter 6: Increasing cultural awareness in nursing students: module development, implementation, and evaluation.

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Abstract

Background

Increasing numbers of training programs aimed at healthcare providers are implementing culturally sensitive care in their curricula. However, while the content of culturally sensitive care is widely debated in the nursing literature, a specific explanation of how students are, and could be, educated is lacking. Research shows that merely increasing knowledge on ethnicity, culture, or migration does not help increase the culturally sensitive behaviour of (future) healthcare providers. On the contrary, it can lead to increased stereotypical thinking. Enhanced critical self-awareness is needed among healthcare providers to overcome barriers such as ‘othering’ (i.e., micro-racism by defining the other in an inferior way).

Aim

A 4-hour module on culturally sensitive care for nursing students was designed, implemented, and evaluated, aiming to increase self-awareness among healthcare providers about othering, racism and exclusion in healthcare and in society.

Methods

This paper describes 1) the content of the module, led by the Johari Window model and the needs and insights from nursing students and healthcare providers, 2) the implementation, and 3) subsequent evaluation among 34 participants.

Findings

The findings are categorized into six themes: understanding differences and prejudices, applying knowledge in the context of nursing practice, acquiring insights through interpersonal engagement, strengths of the sessions, weaknesses and areas for improvement, and overall impressions. The participants evaluated this module positively, identifying success factors (e.g., enhanced awareness of their own positionality) and working points (e.g., imbalance in interaction among students and time constraints).

Discussion

The discussion provides an overview of potential improvements. It highlights the need to expand the module's content and duration, address lecturer’s challenges, and use the evidence for broader implementation, integrating cultural awareness comprehensively into the nursing curriculum for more effective and inclusive care.

Conclusion

This study describes the design, implementation, and evaluation of an educational module to increase nursing students’ (self)awareness and cultural competence, demonstrating notable strengths in improving student awareness, understanding healthcare inequalities, and fostering open communication. The module offers significant potential to enhance culturally sensitive care among nursing students.

Keywords

Critical Self-Awareness, Cultural Competence, Culturally Sensitive Care, Healthcare Providers, Johari Window Model, Nursing Education

6.1 Introduction

In the context of expanding global diversity, research highlights that patients from diverse ethnic-cultural backgrounds encounter significant healthcare challenges (Chukwueke et al., 2022; Eneanya et al., 2022). Studies reveal that patient from ethnic minority background often receive lower quality of care, leading to unmet care needs (Chukwueke et al., 2022; Eneanya et al., 2022; Luiking et al., 2019). Moreover, racial, ethnic, and socio-demographic disparities contribute to delayed diagnoses and lower quality of chronic disease management (Aylward et al., 2021; Nyante et al., 2022). Factors such as language barriers and a shortage of culturally competent healthcare providers worsen these issues (Jones et al., 2022). In addition, inadequate preventive care and limited health education result in undetected health issues due to insufficient screenings and restricted access to culturally adapted education (Raj, 2014). Healthcare providers not being sensitive or responsive to cultural differences further compound the problem, fostering discomfort, misunderstanding, and distrust among patients, negatively impacting the patients' healthcare experiences and treatment effectiveness (Berdai Chaouni, 2021; Wilson et al., 2022). To address these disparities and ensure appropriate care, this study's objective is to design, implement, and evaluate an evidence-based module that enhances culturally sensitive care of future healthcare providers.

Culturally sensitive care involves acknowledging and incorporating diverse cultural beliefs, values, practices, and preferences into healthcare delivery. Its aim is to enhance communication, understanding, and trust between healthcare providers and patients from different backgrounds (Chen et al., 2018; Munoz et al., 2009; Sagar, 2012). This concept is closely linked with cultural competence, which encompasses key elements such as recognizing patient diversity, fostering self-awareness, acquiring cultural knowledge and skills, and demonstrating sensitivity to address cultural barriers (Shen, 2015). In order to provide culturally sensitive care, healthcare providers must be knowledgeable about diverse cultures and possess increased awareness of their own cultural biases and preconceptions, critically reflecting on how these factors may influence interactions with patients from different backgrounds, and overcoming barriers such as 'othering' (i.e., the process of – consciously or unconsciously – perceiving and treating individuals or groups as fundamentally 'other' from oneself, by defining the 'other' in an inferior way) (Berdai Chaouni, 2021; Claeys et al., 2022; Smallheer & Richard, 2024). Culturally sensitive care is linked to improved health outcomes and promotes patient adherence to treatment plans and trust in healthcare providers, thereby enhancing patient satisfaction and ameliorating health disparities (Luiking et al., 2019).

While the importance of culturally sensitive care is widely recognised within healthcare, its actual implementation is challenged due to a number of complexities (Claeys et al., 2021; Markey, 2017). Resource and time constraints, and heavy workloads within healthcare can restrict healthcare providers' capacity to invest the necessary resources in tailoring care to individual needs, thereby hindering the delivery of culturally sensitive care (Luiking et al., 2019). Moreover, healthcare providers struggle to implement culturally sensitive care in practice and are looking for more knowledge on this topic (Claeys et al., 2022; Markey et al., 2018). In addition, personal biases and unconscious stereotypes can pose significant barriers to culturally sensitive care. Even well-intentioned healthcare providers may inadvertently hold biases that can affect their interactions with patients from different cultural backgrounds (Torres, 2006). Overcoming these challenges demands more attention to this topic in education and training programs for healthcare providers (Bell, 2021).

Nevertheless, a thorough evaluation of current training methods in culturally sensitive care indicates the inadequacy of existing programs (Almutairi et al., 2017; Lee & Jun, 2022; Tosun et al., 2021). Training programs often emphasize two domains: the transfer of cultural knowledge and the acquisition of practical skills (Long, 2014; Tosun et al., 2021). When training courses focus on cultural competences, they primarily transfer knowledge about the cultural aspects of 'the other cultures', not recognizing the self-awareness of the healthcare provider (Almutairi et al., 2017; Cai et al., 2017). Moreover, research shows that mere transfer of knowledge concerning different cultures or religious practices does not necessarily translate into more culturally sensitive actions by healthcare providers (Markey et al., 2018). On the contrary, an overemphasis on cultural knowledge can inadvertently reinforce stereotypes, potentially leading to misinterpretations and miscommunication with patients (Berdai Chaouni, 2021). In terms of practical skills as well, there is a particular emphasis on stereotypical habits and traditions, with which certain groups are stereotyped and culturalized (Almutairi et al., 2017). Health inequalities are often not discussed in training on culturally sensitive care – and, if mentioned, these discourses often lack an in-depth analysis of how whiteness and racism are contributing factors to these health inequalities (Ochs, 2023).

Therefore, the aim of this study is **to design, implement and evaluate an evidence-based module to increase the (self) awareness and culturally sensitive care of future healthcare providers, more specifically nursing students**. This intensive module (4 hours) seeks increasing self-awareness among nursing students regarding 'othering', racism and exclusion in society and in healthcare. The aims of this study are: (a) to integrate knowledge and insights from research into an intervention (i.e., the module), (b) to implement the intervention, (c) to evaluate the intervention, and (d) to generate evidence on how to increase the self-awareness of future healthcare providers.

6.2 Methods

A 4-hour intervention was implemented in a nursing bachelor program at a University College in Brussels, Belgium. The ADDIE model (Molenda, 2003) facilitates systematic navigation through each part of the developmental trajectory of the module, starting with an **Analysis** of students' and teachers' needs regarding culturally sensitive care and curriculum gaps. The module was then **Design**ed to increase awareness, followed by the actual **Development** and creation of two sessions. Next, the **Implementation** was discussed. And finally, the **Evaluation** of the module was addressed.

6.2.1 Analysis

<u>Phase 1: Mapping cultural items in the curriculum of the nursing program and detecting gaps in the curriculum (2017-2018):</u>

The goal was to assess the coverage of cultural competences within the nursing program curriculum and identify potential gaps. Simultaneously, focus groups with students were conducted to explore their needs related to cultural competences. The curriculum was systematically examined using the Tool for Assessing Cultural Competence Training (TACCT), a comprehensive 67-item self-administered assessment tool (Lie et al., 2006). This mapping process involved translation and teacher input. The mapping brought to light previously overlooked cultural aspects in the curriculum, inspiring reflections on course improvement.

Phase 2: Analysis of the needs of healthcare providers regarding culturally sensitive care (2019-2020):

The objective was: 1) to deepen understanding of how healthcare providers conceptualize and implement culturally sensitive care, and 2) to identify barriers and facilitators experienced by healthcare providers when delivering such care in practice. Using data from 6 focus groups and 12 individual interviews (with doctors, nurses, social workers, and occupational therapists and with students from nursing, midwifery, and medicine), two papers were written: "Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals" (Claeys et al., 2021), and "Barriers and facilitators in providing care for patients with a migration background" (Claeys et al., 2022). Both studies provided valuable insights into the perceptions of culturally sensitive care, highlighting among others the concepts of awareness and othering.

6.2.2 Design

To achieve the main goal of increasing awareness of ethnic-cultural diversity in healthcare, the conceptual framework of the Johari Window was used (originally developed by Joseph Luft and Harry Ingham, 1955) to illustrate a comprehensive model of awareness and communication within interpersonal relationships (Luft & Ingham, 1961). Over the years, this framework has proven its effectiveness, particularly within the healthcare field (South, 2007). The Johari Window classifies behaviours into four self-awareness dimensions: (1) known to self and others (arena), (2) unknown to self but known to others (blind spots), (3) known to self but unknown to others (façade), and (4) unknown to self and others (hidden areas). Enlarging the arena enhances self-awareness by reducing blind spots, façade, and hidden areas. The educational module, carefully structured to maximize its effectiveness in a limited timeframe, consisted of two two-hour sessions and featured interactive elements like group discussions, reflective exercises, and thought-provoking video clips.

6.2.3 Development

The sessions contained crucial themes, exploring human behaviour, 'othering,' implications of racism, discrimination, and privilege. Participants were encouraged to critically examine their own biases. To limit ideological or political discussions, topics were discussed in the healthcare provider-patient context. The lecturer had thorough experience with the theme and was therefore able to didactically prepare the sessions and guide the group discussions. Table 6 gives a structured overview of the module.

	Analysis: link with results from curriculum-mapping and research	**Design: link with the Johari Window model**	**Development: content and structure of the module**	**Implementation: learning and working methods**	**Planning and time schedule**
1	**General introduction of the first session.** Also practical agreements were made regarding respectful communication and interaction.				10 minutes
2	paper 1 on the concept of culturally sensitive care	The arena (open area, known)	What is culturally sensitive care and why is it problematic that people or groups are culturalized?	applied by video clips and material from written media (newspaper headlines)	First session 20 minutes
3	paper 1 on the concept of culturally sensitive care	The arena (open area, known)	Principle of ‘othering’ as a barrier	shown by video clips and examples from the students, followed by a group discussion	First session 40 minutes
4	paper 2 on the barriers to culturally sensitive care	The arena (open area, known)	‘Othering’ is discussed more in detail, by looking at who 'I' is and who 'the other' is	applied by exercises and video clips	First session 30 minutes
5	**Closing the first session and explaining the assignment**				20 minutes
6	**Introduction of the second session**				20 minutes
7	paper 2 on the barriers to culturally sensitive care	The blind spot and façade	Prevailing implicit and explicit stereotypes and concepts such as whiteness, privilege, and ‘colour’ blindness.	shown by video clips, exercises and a group discussion	Second session 40 minutes
8	paper 2 on the barriers to culturally sensitive care	The unknown (hidden area)	what is unconsciously underlying these mechanisms, and how fear plays a role in maintaining ‘othering’?	This is applied by exercises and a group discussion	Second session 40 minutes
9	**Closing the second session**				20 minutes

Table 6: structured overview of the module

After the first session of the module, the students were asked to complete an assignment in small groups:

- They watched an episode of a TV series and extracted 3 to 5 examples of ‘othering’, discrimination, or exclusion (the lecturer suggested series that were available online or via streaming).
- The students discussed these examples in their group and linked this to their own personal experience.
- The students made a short, recorded reflection with their group (minimum 10 minutes, maximum 30 minutes), which they delivered to the teacher via an electronic learning platform.

6.2.4 Implementation

The intervention took place in the 2nd year of a Bachelor of Nursing (BN) program. The students followed a “Specific Patient Needs” course, which focused on the needs that specific groups of patients may have, and the module was integrated in this course. All second-year students undertaking the BN program were invited to participate in the intervention. This cohort comprised 45 students – 34 of the students took the module, of which 26 were female and 8 were male. All the students were between the ages of 19 and 23. The student group was diverse in terms of ethnicity and cultural backgrounds. The implementation involved the use of video clips, material from written media, student examples, group discussions, and exercises to facilitate learning and working methods.

6.2.5 Evaluation

Survey

Following the two interactive sessions, the participants were invited to take part in the evaluation process: an individual online survey was designed to capture their insights and experiences from the sessions. The survey consisted of open-ended questions aiming to explore nuanced perspectives and reflections from the students. The questions were informed by relevant literature (Smith, 2018), and included questions such as:

- Which part(s) in the module was(were) an added value for you or gave you new insights?
- How will you take this learning with you to your (nursing) practice?
- Which were the module’s most important strengths?
- Which were the module’s most important weaknesses?
- What did you miss in this module?
- Do you feel that these sessions have made you more aware of certain topics like, for example, othering, discrimination, or exclusion?
- Do you have other remarks or ideas that you would like to share?

Data collection from the survey, conducted by the first author, was gathered immediately after the second session of the module to ensure that the participants' impressions and takeaways were still fresh in their minds. The students were informed orally about the importance and purpose of the survey before facilitating easy access via an electronic link. The students were invited to complete the survey via the school's electronic learning platform. To encourage participation, a friendly reminder was sent three days after the initial invitation. As the aim was to generate as many responses as possible, a sample size was not pre-determined. A total of 17 students completed the survey.

Lecturer's logbook

The lecturer of both sessions maintained a written logbook throughout the duration of the module, carefully recording observations both before and after each session. This logbook served as a valuable repository for capturing insights, encompassing the experiences, concerns, and gaps identified during the sessions (Albano et al., 2021). Before each session, the lecturer used the logbook to outline expectations and objectives, providing a structured foundation for the module. By systematically examining the logbook entries, the lecturer was able to identify recurring concerns or gaps in the content, delivery, or participant engagement. This process of continuous self-assessment and improvement enabled timely adjustments to the module. The logbook analysis, therefore, served as a dynamic feedback mechanism that contributed to the program's evolution and refinement, enhancing its impact on the participants.

6.2.6 Data analysis

The experiences of the students collected in the survey, and the assignment were analysed together with the experiences of the lecturer (collected in the logbook), using a thematic content analysis according to Burnard's approach (Burnard et al., 2008). Data were coded using the qualitative data analysis software MAXQDA©. The construction of the coding tree was based on the questions in the survey. Following the initial coding process, the authors engaged in discussions to refine and deepen the understanding of the coded data. This iterative analysis was then followed by two subsequent rounds of analysis, facilitating a comprehensive and nuanced exploration of the students' and lecturer's experiences and perspectives. All authors possess a thorough understanding of qualitative research methods and thematic content analysis, and furthermore, all are lecturers in healthcare or research programs.

6.2.7 Ethical considerations

This study is part of the larger Diverse Elderly Care research project, which examines culturally sensitive dementia care for migrants in Brussels, from the perspectives of patients, family carers and healthcare providers. Ethics approval was granted by the Ethics Committee of the University Hospital of Brussels (CE 2016-105). Participation was voluntary, and the students had the right to refuse participation without this compromising their student status or grades. A student's completion of the survey was considered evidence of consent. Both the module and the survey were non-compulsory. The questionnaire data were processed anonymously. Completing the assignment was voluntary. Not completing the assignment did not negatively impact the students' rating for this course.

6.3 Results

This section provides a detailed description of the findings following the module's implementation. It presents the results of the students' survey responses and their assignments, and shares insights learned from the lecturer's experiences based on the logbook.

6.3.1 Survey with open questions

Through an in-depth analysis of the survey responses, the findings are categorized into six themes: understanding differences and prejudices, applying knowledge in the context of nursing practice, acquiring insights through interpersonal engagement, strengths of the sessions, weaknesses and areas for improvement, and overall impressions. The following paragraphs briefly present these themes.

Understanding differences and prejudices

The students learned from both sessions that everyone is different and that sometimes prejudices are expressed without one being aware. The students also indicated that they learned new terminology and that they now have a better understanding of the mechanisms behind racism and discrimination. As one student stated: *"I learned new terms and also saw how racism and discrimination work."* Moreover, they learned the concept of 'othering', and that there are different ways of expressing racism.

Applying knowledge in the context of nursing practice

In the way the students took the content of these sessions to their nursing practice, the students replied that they understand from these sessions that, due to the context of healthcare and through the relationship of healthcare provider and patient, inequality is sometimes more pronounced than in other situations. The students wanted to treat every care recipient in a respectful manner and want to consider the patients' needs. As formulated by one student: *"Everyone must be approached in a respectful manner and the needs of the patient must be taken into account."* They realized that every patient is different and deserves an appropriate individualized approach. Some students expressed a desire to increase their awareness of their own biases that could impact their nursing practice. They acknowledged acting shy and low-profile at times during patient contact, and they expressed a goal to overcome this by engaging more with individuals from different cultures during their internships. They aimed to be more intentional in their actions during internships and wanted to enhance their overall awareness in daily life regarding their thoughts about people who are different from them.

Acquiring insights through interpersonal engagement

The students indicated that they learned mainly from the interactions with their fellow students and from the opinions and experiences of the fellow students during the sessions. As one student stated: *"When you hear from other students… how they are disadvantaged. I was not aware of this."* They learned that the term 'culturally sensitive care' is not desirable because it puts too much emphasis on the cultural aspects of one's identity. They also learned that some questions, even though they are well-intentioned, can come across as inappropriate to certain people because people are not aware of what these questions mean (e.g., 'where are you from?'). Some students indicated that they are already aware to some extent of some of the themes explored in the module, but that these sessions provide a deepening of existing knowledge and awareness.

In particular, the videos and video fragments provided added value and new insights. For some students, both entire sessions – including the explanations, examples, video fragments and exercises – were of added value. The fact that the students had to formulate their own opinions and listen to the opinions of others also led to new insights among the students. As one student formulated: *“It was good that our opinions as students were asked for and listened to.”*

Strengths of the module

The students experienced several strengths of these sessions. A primary strength was the diverse class group in terms of culture, ethnicity, and gender, because this diversity generated different opinions on the different themes during the interactive moments. It was also considered a strength that the students’ opinions were sought and that everyone was allowed to express their opinion, and, for instance, that students could also provide examples. The openness and honest atmosphere experienced during the sessions, and the fact that the discussions were conducted in a non-hurtful way, was also considered a strength of these sessions. An example was cited in the form of the exercise on privileges because it stimulated the students to think about their own situation and privileges. Some examples from the sessions were also affirmative for some students, because they showed the students that they are already doing certain things well.

Weaknesses and areas for improvement

Weaker points of these sessions were that some students found it disturbing that they brought a lot of input to the sessions, but that other students answered little and contributed very little to the lesson. Some students also felt that there was too little interaction with some topics and that the exercise on privileges could be discussed even more extensively. Themes that were not discussed broadly concerned various forms of discrimination, such as sexism. Students also indicated that other current issues could also be addressed, such as gender equality or LGBTQ+ related aspects.

Overall impressions

Most students answered positively when asked whether these sessions had made them more aware of topics such as othering, discrimination, or inequalities. The students felt that through these sessions they became more aware of a number of issues, including the fact that (in society) racist remarks are very often made unknowingly and unintentionally. Some students indicated that they were already aware of those topics, either due to their own experiences or because their parents had already taught them about existing inequalities. Notwithstanding, some students indicated that, although they were already aware, they found it interesting to talk about these topics with others and in the context of healthcare.

6.3.2 Video reflections from the students’ assignment

Most students reflected positively in their assignment about whether these sessions and the assignment had made them more aware of topics such as othering, discrimination or inequalities. The students felt that through these sessions they became more aware of a number of issues, including the fact that (in society) racist remarks are very often made unknowingly and unintentionally. Sometimes these comments are also made consciously and deliberately in society, as this student notes, making the connection between the assignment, social debates and the content of the module: *"This [example from the series in the assignment] and other* *discriminatory language from power figures (such as, for example, referring to Mexicans as drug dealers) contributes to the normalization of 'othering' and the exclusion of certain groups of people."*

6.3.3 The lecturer's logbook

Self-awareness and awareness of one's own feelings during both sessions of the module

Self-awareness and emotional awareness during the sessions were crucial aspects. The lecturer acknowledged her own background – characterized by a lack of migration history and being of a white ethnicity – in the context of the module's themes, which encompass subjects like othering, racism, and discrimination. Initially, this self-awareness initiated feelings of fear and extreme caution within the lecturer, resulting in an increased focus on the choice of words throughout the sessions. The lecturer addressed these emotions with the group, emphasizing that, while the lecturer lacked personal experiences of racism or discrimination, these themes were shared narratives of our current society in which everyone plays a role. It was experienced as positive that the lecturer's positionality was mentioned, and it was beneficial to the group's safety and openness that this was stated at the start of the module.

Throughout the sessions, the lecturer remained conscious of the difficult task of navigating the various roles while discuss a sensitive topic. This involved providing explanations, offering examples, and facilitating exercises, all while also moderating group discussions and ensuring timely progress to successfully conclude the sessions within the designated timeframe. The Johari Window appeared to be a good format by which to give this content a structured form and teach it to students.

Interactions with the group

In this case, this group was comprised of students who participated in this module as it constituted a part of their course curriculum. The nature of the module could have had an impact on student engagement and classroom interaction. The level of commitment and opportunities for interaction may be different among a group that enrols voluntarily in an additional course. Conveying the message about othering, racism, and discrimination could be challenging for individuals who have not yet encountered these issues previously, either through personal experiences or conscious observation. It is an advantage for the lecturer to have prior knowledge of the class group and to be familiar with the student group, in order to be able to respond to their reactions and interactions to some extent.

Practical aspects of the module

Regarding the practical aspects of this module, the available time felt quite limited for providing comprehensive content. Given the constraints of this limited timeframe, and the division of the module into only two sessions, certain exercises had to be shortened, and some discussions had to be concluded prematurely. In the context of group discussions, it could be a possibility to consider avoiding the division into two sessions and instead delivering the sessions in a single, uninterrupted time block. Furthermore, the sessions were best delivered in a classroom space that offers opportunities and flexibility to move during the exercises. The group's size also played a role in the exercises and group discussions – and it should therefore be limited to approximately 30 students per session, taking into account the size of the total group of students.

Now that the results have been presented, the following section discusses the broader implications.

6.4 Discussion

The aim of the study was to design, implement and evaluate an educational module on othering and racism, in order to increase nursing students' (self)awareness and cultural competence. The following sections discuss: (1) the added value of the intervention and how the evidence generated from the evaluation will be used to refine the intervention and implement it on a wider scale, and (2) how to best integrate cultural awareness in the nursing curriculum.

6.4.1 Added value of the intervention, limitations, and implementing the intervention on a wider scale

The intervention demonstrated strengths in enhancing student awareness, self-awareness, and understanding healthcare disparities. It also promoted open and non-offensive communication among students and increased the lecturer's awareness of their positionality. However, identified areas for improvement include uneven student interactions, time constraints limiting in-depth discussions, and students expressing interest in expanding the module's content and duration. Additionally, addressing challenges faced by the lecturer in managing multiple roles suggests the potential benefits of increasing the number of lecturers. Creating a safe space for students to share experiences of racism and exclusion is also recommended. The educational module was implemented on a small scale within a single nursing program. Expanding this module on a larger scale and incorporating it into different programs across various healthcare disciplines would be recommended (Hamed et al., 2022; Markey et al., 2019; Seeleman, 2014).

The results indicate that a culturally sensitive care module enhances awareness and self-awareness among nursing students. Introducing students in this aspect of nursing education provides insights into their awareness and position as healthcare providers, particularly when caring for patients with different ethnic-cultural backgrounds. Successful implementation requires well-trained lecturers, a well-framed module, and guided interaction during the sessions, with the Johari Window serving as a suitable structure (Luft & Ingham, 1961).

Increased awareness enables students to offer more tailored and empathetic care while challenging prejudices and biases. As nursing students encounter the complexities of cultural competences, they become more aware to their own perspectives, enhancing sensitivity and respect for the patient (Jeffreys, 2016). The module enhances awareness and raises empathy and inclusivity, which can contribute to improved patient satisfaction and overall healthcare quality (Červený et al., 2022; Luiking et al., 2019).

Looking ahead, the results from this implementation and evaluation will serve as a resource for its implementation on a broader scale. This will involve consolidating the strengths and addressing the identified limitations of the module to ensure its effectiveness in a wider context.

6.4.2 Integration of cultural awareness in the nursing curriculum

This 4-hour module was promising – but, in order to develop deep cultural competence among nursing students, such a module should be integrated in the nursing program as a comprehensive and ongoing part of the curriculum, not merely as a stand-alone module (Jeffreys, 2016; Nematollahi et al., 2022).

Therefore, all nursing teachers must have sufficient cultural competence (Luukkonen et al., 2023; Paric et al., 2021). Lecturers should be well-trained themselves, and well-supported in cultural competence to serve as role models for the students. They should encourage open dialogues on cultural issues, creating an environment where students feel comfortable discussing their own biases and learning from one another. The teachers must understand that their own identities and (self-)awareness have an influence on their teaching practices related to cultural competences (Bell, 2021).

Moreover, a regular update of course materials is necessary to reflect best practices in culturally sensitive care and current research – for example, the current emphasis on culturally responsive care (Markey et al., 2023). It can also be useful to establish partnerships with local healthcare organizations serving diverse populations, offering students opportunities for clinical placements that reinforce cultural awareness in a practical setting (Smith, 2018).

Finally, research indicates that more attention to the relational aspect of the profession in simulation education can also lead towards increased awareness among students (Knutsson et al., 2022; Roberts et al., 2014).

6.5 Conclusion

This study describes the design, implementation and evaluation of an educational module to increase nursing students' (self)awareness and cultural competence. The module has shown several notable strengths, such as the improvement in the students' awareness and a deeper understanding of healthcare inequalities. In addition, the program proved effective in raising open and non-offensive communication among students, while simultaneously increasing the awareness of their own positionality. The students' feedback indicated a strong desire to explore related themes, underlining the necessity for expanding the module in terms of both content and duration. Another important consideration is the challenges faced by the lecturer in managing multiple roles during the sessions, highlighting the potential benefits of increasing the number of lecturers. Looking towards the future, the evidence derived from this implementation will serve as a key resource for refining the module and paving the way for its implementation on a broader scale.

References

Albano, G., Antonini, S., Coppola, C., Dello Iacono, U., & Pierri, A. (2021). 'Tell me about': A logbook of teachers' changes from face-to-face to distance mathematics education. *Educational Studies in Mathematics*, *108*(1/2), 15-34. https://doi.org/10.1007/s10649-021-10108-2

Almutairi, A. F., Adlan, A. A., & Nasim, M. (2017). Perceptions of the critical cultural competence of registered nurses in Canada. *BMC Nursing*, *16*, 1-9. https://doi.org/10.1186/s12912-017-0242-2

Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder. *Journal of Developmental and Behavioral Pediatrics*, *42*(8), 682-689. https://doi.org/10.1097/DBP.0000000000000996

Bell, B. (2021). White dominance in nursing education: A target for anti-racist efforts. *Nursing Inquiry*, *28*(1), e12379. https://doi.org/10.1111/nin.12379

Berdai Chaouni, S. (2021). *Grasping Fading Memories of a Motherland: Capturing Dynamic Care Realities of Older Labor Migrants with Dementia*. [PhD Thesis].

Burnard, P., Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Analysing and presenting qualitative data. *British Dental Journal*, *204*(8), 429-432. https://doi.org/10.1038/sj.bdj.2008.292

Cai, D., Kunaviktikul, W., Klunklin, A., Sripusanapan, A., & Avant, P. K. (2017). Identifying the essential components of cultural competence in a Chinese nursing context: A qualitative study. *Nursing & Health Sciences*, *19*(2), 157.

Červený, M., Kratochvílová, I., Hellerová, V., & Tóthová, V. (2022). Methods of increasing cultural competence in nurses working in clinical practice: A scoping review of literature 2011-2021. *Frontiers in Psychology*, *13*, 936181. https://doi.org/10.3389/fpsyg.2022.936181

Chen, H.-C., Jensen, F., Measom, G., Bennett, S., Nichols, N. D., Wiggins, L., & Anderton, A. (2018). Factors Influencing the Development of Cultural Competence in Undergraduate Nursing Students. *Journal of Nursing Education*, *57*(1), 40-43. https://doi.org/10.3928/01484834-20180102-08

Chukwueke, U. N., Hervey-Jumper, S., & Porter, A. (2022). Disparities and Inequities Among Patients with Central Nervous System Tumor. *Hematology/Oncology Clinics*, *36*(1), e1-e8. https://doi.org/10.1016/j.hoc.2021.10.002

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2021). Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals. *Journal of Transcultural Nursing*, *32*(5), 484-492. https://doi.org/10.1177/1043659620970625

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & Donder, L. D. (2022). Barriers and facilitators in providing care for patients with a migration background. *Journal of Clinical Nursing*. https://doi.org/10.1111/jocn.16491

Eneanya, N. D., Boulware, L. E., Tsai, J., Bruce, M. A., Ford, C. L., Harris, C., Morales, L. S., Ryan, M. J., Reese, P. P., Thorpe, R. J., Morse, M., Walker, V., Arogundade, F. A., Lopes, A. A., & Norris, K. C. (2022). Health inequities and the inappropriate use of race in nephrology. *Nature Reviews Nephrology*, *18*(2), Article 2. https://doi.org/10.1038/s41581-021-00501-8

Hamed, S., Bradby, H., Ahlberg, B. M., & Thapar-Björkert, S. (2022). Racism in healthcare: A scoping review. *BMC Public Health*, *22*(1), 988. https://doi.org/10.1186/s12889-022-13122-y

Jeffreys, M. (2016). *Teaching Cultural Competence in Nursing and Health Care: Inquiry, Action, and Innovation: Vol. Third edition*. Springer Publishing Company. https://search.ebscohost.com/login.aspx?direct=true&db=e000xww&AN=1104182&lang=nl&site=eds-live&scope=site&authtype=sso&custid=s3945784

Jones, C. J., Paudyal, P., West, R. M., Mansur, A. H., Jay, N., Makwana, N., Baker, S., & Krishna, M. T. (2022). Burden of allergic disease among ethnic minority groups in high-income countries. *Clinical & Experimental Allergy*, *52*(5), 604-615. https://doi.org/10.1111/cea.14131

Knutsson, S., Axelsson, J., & Lindqvist, G. (2022). An application of the caritative caring approach – nursing students' experiences of practising caring and uncaring encounters by simulation at a clinical training centre. *International Journal of Qualitative Studies on Health and Well-being*, *17*(1), 2100610. https://doi.org/10.1080/17482631.2022.2100610

Lee, J., & Jun, W. H. (2022). Effect of compassion competence on cultural competence in student nurses: Mediating effect of professional nursing values. *Journal of Professional Nursing*, *41*, 134-139. https://doi.org/10.1016/j.profnurs.2022.05.003

Lie, D., Boker, J., & Cleveland, E. (2006). Using the tool for assessing cultural competence training (TACCT) to measure faculty and medical student perceptions of cultural competence instruction in the first three years of the curriculum. *Academic medicine : journal of the Association of American Medical Colleges*, *81*(6), 557-564. https://doi.org/10.1097/01.ACM.0000225219.53325.52

Long, T. (2014). Influence of international service-learning on nursing student self-efficacy toward cultural competence. *The Journal of Nursing Education*, *53*(8), 474-478. https://doi.org/10.3928/01484834-20140725-02

Luft, J., & Ingham, H. (1961). The Johari Window: A graphic model of awareness in interpersonal relations. *Human relations training news*, *5*(9), 6-7.

Luiking, M., Heckemann, B., Ali, P., Doorn, C., Ghosh, S., Kydd, A., Watson, R., & Patel, H. (2019). Migrants' Healthcare Experience: A Meta-Ethnography Review of the Literature. *Journal of Nursing Scholarship*, *51*(1), 58-67. https://doi.org/10.1111/jnu.12442

Luukkonen, A.-L., Kuivila, H., Kaarlela, V., Koskenranta, M., Kaučič, B. M., Riklikiene, O., Vizcaya-Moreno, F., Pérez-Cañaveras, R. M., Filej, B., Oikarainen, A., Kääriäinen, M., & Mikkonen, K. (2023). Mentors' cultural competence at mentoring culturally and linguistically diverse nursing students in clinical practice: An international cross-sectional study. *Nurse Education in Practice*, *70*, 103658. https://doi.org/10.1016/j.nepr.2023.103658

Markey, K. (2017). *An exploration of nurses' experiences of caring for people from different cultures in Ireland*.

Markey, K., Macfarlane, A., & Manning, M. (2023). Time to re-envisage culturally responsive care: Intersection of participatory health research and implementation science. *Journal of Advanced Nursing*, *79*, n/a-n/a. https://doi.org/10.1111/jan.15821

Markey, K., Tilki, M., & Taylor, G. (2018). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *27*(1-2), e259-e268. https://doi.org/10.1111/jocn.13926

Markey, K., Tilki, M., & Taylor, G. (2019). Resigned indifference: An explanation of gaps in care for culturally and linguistically diverse patients’. *Journal of Nursing Management (John Wiley & Sons, Inc.)*, *27*(7), Article 7. https://doi.org/10.1111/jonm.12830

Molenda, M. (2003). In search of the elusive ADDIE model. *Performance Improvement*, *42*(5), 34-36. https://doi.org/10.1002/pfi.4930420508

Munoz, C. C., DoBroka, C. C., & Mohammad, S. (2009). Development of a multidisciplinary course in cultural competence for nursing and human service professions. *The Journal of Nursing Education*, *48*(9), 495-503. https://doi.org/10.3928/01484834-20090610-03

Nematollahi, M., Farokhzadian, J., Dehghan Nayeri, N., Darban, F., & Faramarzpour, M. (2022). Explaining the educational challenges in the path of cultural competence: The experiences of Iranian nursing students. *Journal of Professional Nursing*, *42*, 140-147. https://doi.org/10.1016/j.profnurs.2022.06.011

Nyante, S. J., Abraham, L., Aiello Bowles, E. J., Lee, C. I., Kerlikowske, K., Miglioretti, D. L., Sprague, B. L., Henderson, L. M., & Breast Cancer Surveillance Consortium. (2022). Diagnostic Mammography Performance across Racial and Ethnic Groups in a National Network of Community-Based Breast Imaging Facilities. *Cancer Epidemiology, Biomarkers & Prevention: A Publication of the American Association for Cancer Research, Cosponsored by the American Society of Preventive Oncology*, *31*(7), 1324-1333. https://doi.org/10.1158/1055-9965.EPI-21-1379

Ochs, J. H. (2023). Addressing health disparities by addressing structural racism and implicit bias in nursing education. *Nurse Education Today*, *121*, 105670. https://doi.org/10.1016/j.nedt.2022.105670

Paric, M., Kaihlanen, A.-M., Heponiemi, T., & Czabanowska, K. (2021). Nurse teacher’s perceptions on teaching cultural competence to students in Finland: A descriptive qualitative study. *Nurse education today*, *99*, 104787. https://doi.org/10.1016/j.nedt.2021.104787

Raj S. Bhopal. (2014). *Migration, Ethnicity, Race, and Health in Multicultural Societies: Vol. Second edition*. OUP Oxford. https://search.ebscohost.com/login.aspx?direct=true&db=e000xww&AN=678148&lang=nl&site=eds-live&scope=site&authtype=sso&custid=s3945784

Roberts, S.-G., Warda, M., Garbutt, S., & Curry, K. (2014). The Use of High-Fidelity Simulation to Teach Cultural Competence in the Nursing Curriculum. *Journal of Professional Nursing*, *30*(3), 259-265. https://doi.org/10.1016/j.profnurs.2013.09.012

Sagar, P. (2012). *Transcultural Nursing Theory and Models: Application in Nursing Education, Practice, and Administration (Springer, 2012)*.

Seeleman, M. C. (2014). *Cultural competence and diversity responsiveness: How to make a difference in healthcare?* Universiteit van Amsterdam.

Shen, Z. (2015). Cultural Competence Models and Cultural Competence Assessment Instruments in Nursing: A Literature Review. *Journal of Transcultural Nursing*, *26*(3), 308.

Smallheer, B., & Richard, -Eaglin Angela. (2024). Implementation of Cultural Awareness and Cognitive Bias Training Within Graduate Nursing Programs. *Journal of Nursing Education*, *0*(0), 1-4. https://doi.org/10.3928/01484834-20240318-03

Smith, L. S. (2018). A nurse educator’s guide to cultural competence. *Nursing Management*, *49*(2), 11-14. https://doi.org/10.1097/01.NUMA.0000529933.83408.06

South, B. (2007). Combining mandala and the Johari Window: An exercise in self-awareness. *Teaching and Learning in Nursing*, *2*(1), 8-11. https://doi.org/10.1016/j.teln.2006.10.001

Torres, S. (2006). Elderly Immigrants in Sweden: 'Otherness' Under Construction. *Journal of Ethnic & Migration Studies*, *32*(8), 1341-1358. https://doi.org/10.1080/13691830600928730

Tosun, B., Yava, A., Dirgar, E., Şahin, E. B., Yılmaz, E. B., Papp, K., Tóthova, V., Hellerova, V., Prosen, M., Licen, S., Karnjus, I., Tamayo, M. D. B., Leyva-Moral, J. M., Claeys, A., & Tricas-Sauras, S. (2021). Addressing the effects of transcultural nursing education on nursing students' cultural competence: A systematic review. *Nurse Education in Practice*, *55*, 103171. https://doi.org/10.1016/j.nepr.2021.103171

Wilson, K., Turkelson, C., Logan, T., & Rhodes, N. (2022). Racism and Professional Competence: Nursing Students in Interracial Evaluations. *Journal of Nursing Education*, *61*(1), 41-45. https://doi.org/10.3928/01484834-20211203-05

Chapter 7: Discussion

This chapter presents the general discussion of the dissertation. Section 1 provides an overview of the main findings in relation to the research questions. Section 2 elaborates on the implications for policy and practice and presents recommendations. Section 3 presents reflections on the methodology of the studies and presents suggestions for further research. The chapter concludes with the general conclusion in section 4.

7.1 Main findings in relation to the research questions

This chapter gives an overview of the main findings on the three research questions. First, in discussing the perception and implementation in practice of culturally sensitive care by healthcare providers, two questions are answered, namely how healthcare providers perceive and implement culturally sensitive care in practice, and what specific barriers and facilitators they encounter, on the individual level, from the care organisation and from the healthcare system. Second, the experiences of professional care of informal carers with a migration background are discussed. Third, educational strategies are discussed for increasing self-awareness and critical reflection among student healthcare providers. Fourth, overarching findings are presented and discussed.

7.1.1 How do healthcare providers define, perceive, and deliver culturally sensitive care?

Chapter 3 and 4 point out that healthcare providers have a narrow and stereotypical perception of culturally sensitive care, emphasizing the inconveniences. This perception becomes also visible in their care practices, where barriers to culturally sensitive care are more likely to be considered than the facilitators. However, there are also healthcare providers who perceive culturally sensitive care as an enrichment.

A narrow and stereotypical perception

Chapter 3 shows that healthcare providers have a **narrow perception** of culturally sensitive care. It is perceived more as a **checklist of practical actions**, rather than as an empathic and sensitive attitude. This can be confirmed from the findings in chapter 5, where informal carers experience distant and routine professional care. If the healthcare provider views culturally sensitive care as a checklist of practical actions, then when drafting this hypothetical checklist, they are guided by the **stereotypical image of 'the other'** that they hold in their perception of culturally sensitive care. The **‘cultural’ in culturally sensitive actions is primarily interpreted as actions related to religion**, and likewise the target group for these actions is often **narrowed to Muslim patients.** This connects with the current framing in Western societies, where 'culture' equals 'migrant' and where 'migrant' equals 'Muslim' (Fadil, 2019; Helbling, 2012; Shaker & Ahmadi, 2022). This points to a stereotypical, narrow, and static interpretation of the concept of 'culture' in the context of culturally sensitive care. These findings mostly apply to the white healthcare providers from the studies in chapters 3 and 4. The findings also indicate that **healthcare providers with a migration background have a broader and more diverse group in**

mind when considering the concept of culturally sensitive care. They associate culture less often to religion and were more likely to view 'other cultures' as other ethnic groups (e.g., patients from Eastern Europe or Central Africa).

Further, chapter 3 demonstrates that most healthcare providers (with and without a migration background) perceive culturally sensitive care as something that is **difficult, that needs more effort and more time.** They **need more knowledge** (e.g. cultural knowledge), but little efforts are made to gain more knowledge, which is confirmed in other studies (Markey et al., 2019; Mollah et al., 2018). This leads to feelings of **uncertainty** in the healthcare provider, **resulting in assumptions, acting shy, or on the contrary overacting**. The shyness or the overacting, as described in Chapter 3, is also seen in other research, and can explained by disengagement strategies from the healthcare provider to deal with the uncertainty. By masking (urge to act) or distancing (acting shy), healthcare providers are searching strategies to cope with the uncertainty they experience when providing care for culturally and linguistically diverse patients. A third disengagement strategy mentioned is to focus on the routine aspect of the job, as also explained in the next paragraph (Markey et al., 2019).

A task-oriented and optional implementation

Chapter 3 and 4 show that, in line with their narrow perception with a focus on practical actions, culturally sensitive care is implemented in daily care practice **more in a task-oriented way, rather than from a relationship-oriented approach**. Chapter 5 also confirms these findings, where informal carers share their experiences about cold-hearted care, with more importance on rules and procedures than on professional engagement. Halldorsdottir (1996) discusses this lack of engagement and humanity in care from the model of ‘Caring and uncaring encounters’, which explains that an uncaring encounter is characterised by insensitivity and disinterest in the other, coldness in the connection and lack of humanity in care situations (Halldorsdottir, 1996; Söderman et al., 2018). In contrary to what the name suggests, the model of caring and uncaring encounters is not a dichotomy, but can rather be seen as a continuum about how to be and interact with each other (Söderman et al., 2018).

Chapter 3 demonstrates that healthcare providers perceive culturally sensitive care from a narrow approach, guided by the stereotypical image of 'the other’. From this stereotypical perspective, it was also noted in chapter 4 that general actions from a patient (e.g. refusal of a proposed care offer) are framed as a cultural barrier in healthcare. This strong focus on ‘the (cultural) other’ can be explained by the concept of **othering**. Othering can be defined as “a *simultaneous construction of the self or in-group, and the other or out-group in mutual and unequal opposition through identification of some desirable characteristics that the self (in-group) embodies, and that the other (out-group) lacks”* (Woodward, 2018, p.429). Othering is an implicit and largely unconscious process by which racial identities, stereotypes and stigmas are attached to specific individuals and groups (Brons, 2015; Coates, 2022). The implicit and unconscious nature of othering is also demonstrated in the findings of chapter 3. However, precisely by engaging in othering unconsciously, one is not aware of the power imbalance that underlies it. This exact process of separating 'We' from 'Other' can be seen as creating hierarchies of power, implying that the 'Other' is (implicitly) inferior (Anjorin & Busari, 2023). From a postcolonial perspective, group distinctions result from historical power relations, through which othering also becomes part of societal discourse and institutional structures (Akbulut & Razum, 2022; Coates, 2022). In addition, this can also take other forms such as **racist and discriminatory** microaggressions and behaviour, explicit or implicit racism, and xenophobia (Baak, 2019; Coates, 2022; Pérez Huber & Solorzano, 2015). Following the definition of Pérez Huber and Solorzano (2015), racial microaggressions can be defined as: *'A form of systemic, everyday racism used to keep those at the racial margins in their place. [Racial microaggressions] are: (1) verbal and non-verbal assaults directed toward People of Colour, often carried out in subtle, automatic or unconscious forms; (2) layered assaults, based on race and its intersections with gender, class, sexuality, language, immigration status, phenotype, accent, or surname; and (3) cumulative assaults that take a psychological, physiological, and academic toll on People of Colour.'* (Pérez Huber & Solorzano, 2015, p. 2). Chapter 3 demonstrates that there is a **lack of awareness** among healthcare providers about othering and implicit bias, but also about their own frame of reference and how they view themselves and others from the point of view of ethnic-cultural diversity, and how this might lead to culturally insensitive care and racial discriminatory behaviour. This othering describes behaviour of the individual healthcare provider. However, this healthcare provider always works in interaction with other healthcare providers and often also within a healthcare or care organisation.

Chapter 4 shows that healthcare providers perceive a **lack of leadership from the management** of their care organisation about the implementation of culturally sensitive care. Individual healthcare providers **lack support and flexibility from their care organisation** when they take initiatives towards culturally diverse patients. As a result, organisations give the impression to individual healthcare providers that these actions are at their own responsibility, and on the contrary that they can even be held accountable for this by their manager, as was also shown in chapter 4 and also confirmed in other research (Dell'aversana & Bruno, 2021). The efforts of multilingual healthcare providers to overcome language barriers are also not rewarded or acknowledged by the care organisation, which means that this support in translating is experienced an additional task for them in an already over-demanding work environment. Valuing the competences and differences of healthcare providers is proven to be a more preferable strategy (Harrison et al., 2020) The disengagement strategies mentioned earlier (e.g. acting shy, overacting, task-oriented approach) pass unnoticed by the management, and if they are noticed, then the healthcare provider will not be held accountable for this. Unintentionally it leads to substandard care for the patient, which also aligns with the findings in chapter 4 en 5 (Markey et al., 2019).

Chapter 4 points out that both individual healthcare providers and healthcare organizations have a **feeling of non-importance** regarding culturally sensitive care. If healthcare providers take actions, it is at their own responsibility and there may be consequences from their supervisor. But there are no consequences for not providing culturally sensitive care, or even not for providing culturally insensitive care. Chapter 4 also indicates that healthcare providers do not experience culturally sensitive care as a strategic goal for their policy. This perpetuates the idea of non-importance around culturally sensitive care, for the healthcare provider, the healthcare organisation and the healthcare policy. This strengthens the result that culturally sensitive care is **seen as optional from the healthcare provider's perspective**. The idea of non-importance and non-urgence reinforces the attitude of care organisations that culturally sensitive care comes naturally if the organisation is multicultural in terms of employees, but more explicit actions are required (Akpapuna et al., 2020; Hassen et al., 2021). The awaiting attitude of management indicates a lack of awareness at the management level in healthcare organisations (Dell'aversana & Bruno, 2021). In addition, healthcare and care provision is under pressure due to economic cuts and staff shortages. This shifts the **focus to 'essential tasks'**, which confirms to healthcare providers and healthcare organizations that culturally sensitive care is optional and not important in the perspective of 'essential tasks'. Moreover, it was also shown that time pressure is also used by healthcare providers as an excuse to not provide culturally sensitive care (Markey et al., 2019). There is also the perception in policy in general in Belgium and in Flanders that current and future diversity is not a key issue (in contrast to migration, for which the policy view is that this must be reduced).

A perception of enrichment and opportunities

Although the findings show that healthcare providers often have a narrow and stereotypical perception of culturally sensitive care, the findings show that **another perception and implementation is also possible** in healthcare providers.

Chapters 3 and 4 demonstrate that healthcare providers (both with and without a migration background) who perceive culturally sensitive care from an open-minded point of view are more likely to see **diversity as an enrichment or an opportunity for enrichment**. Their perception on care provision starts from an open and respectful attitude towards patients with a migration background, and an open point of view, which translates in skills like thinking out-of-the-box and flexibility, as is also experienced and appreciated by the informal carers in the findings in chapter 5. Communication is an important skill for these healthcare providers, with developed **communication skills, or the intention to develop them**. The same goes for language barriers: these healthcare providers either speak multiple languages, or at least try to bridge the language barrier (Schouten et al., 2023). This attitude is in line with Halldorsdottir's description of a **caring encounter**, which is characterized by communication skills, recognizing the unique person, being present and showing respect and true negotiation of care based on the unique needs (Halldorsdottir, 1996; Söderman et al., 2018).

Chapter 3, 4 and 6 show that these healthcare providers who look at culturally sensitive care with an open mind mostly have **self-awareness and critical awareness of their own frame of reference**. This finding follows the viewpoint that culturally sensitive care starts with the 'self' and not with 'the other' (Markey & Tilki, 2007). When they want to explain this point of view, they usually do so by referring to how they were raised, their education, travelling or years of work experience.

Initiatives that, according to healthcare providers, facilitate the provision of culturally sensitive care are rarely discussed, as the findings in chapter 4 show. If they are mentioned, they concern individual initiatives that are **not structural**. Sometimes facilitators are also mentioned in a hypothetical manner, e.g. structural management decisions that would allow flexibility in a healthcare organisation.

The finding that engagement in healthcare providers relies on individual initiatives rather than on structural management is also experienced by the informal carers, as the following part shows.

7.1.2 How do informal carers of patients with a migration background experience the professional care they receive?

Informal carers looking after an older person with dementia and a migration background are seeking professional care to help them organise and provide the best possible care, as shown in chapter 5. Being an **informal carer** in today's society involves **many tasks and responsibilities** (Mazaheri et al., 2011; Shrestha et al., 2023). The informal carer is therefore looking for support from professional care to take on these care tasks together, with the aim to provide quality care for the older person. The findings in chapter 5 show that **what they are looking for in**

professional care is a care alliance with the healthcare provider, where warm relationships and caring encounters take place, with respect, flexibility and open attitude. This aligns with the open-minded perception of culturally sensitive care in some healthcare providers, as pointed out in chapter 3.

Informal carers also aim to create a sense of home for the older person, fostering familiarity. This is often expressed through a familiar meal, recognizable language, or something or someone in the environment that feels familiar. In this way they hope to have **personalised care for the older person** (Duran-Kiraç et al., 2023; Jutlla, 2015). Informal carers search for and provide **familiarity** within the standard care options due to the lack of care tailored to the needs of older persons with a migration background. (Sagbakken et al., 2018). Even though the informal carer and the older person place great importance on recognizable aspects in nutrition, language, and environment, it is important to note that tailored care involves more than just these occasional examples. Tailored care also involves adapting organisationally to the needs of the patient (Blix & Munkejord, 2022; Jutlla, 2015). This can, for example, involve adjusting the daily schedule or division of tasks to meet individual needs. In addition, chapter 5 demonstrates that informal carers experience culturally insensitive care, where their needs and questions are ignored or refused. This aligns with the findings from chapters 3 and 4, highlighting that healthcare provision often views culturally sensitive care as optional, an additional rather than an essential part of basic quality care. Further, informal carers have encountered healthcare providers lacking cultural competence, displaying othering, implicit or explicit racial discrimination.

Some informal carers find healthcare providers committed to offering tailored care as best as possible. However, this engagement is not structural, so other informal carers encounter a different side of formal care provision. They experience uncaring encounters and **cold-hearted and substandard care**, which was experienced in different care settings, as chapter 5 points out. When formal care provision falls short in providing care in a respectful and qualitative way, **informal care must fill in the gaps**, which means that informal carers must take on additional tasks, as also seen in other studies (Duran-Kiraç et al., 2022; Duran-Kiraç et al., 2023; Stenberg & Hjelm, 2023).

The experiences with cold-hearted and substandard care provision align with two previously mentioned aspects. Firstly, it reflects the model of caring and uncaring encounters, where descriptions of uncaring encounters match the experiences of informal carers, such as disinterest, insensitivity towards the other, coldness in the connection, and a lack of humanity in care situations (Halldorsdottir, 1996; Söderman et al., 2018). Secondly, the disengagement strategies previously mentioned, in which healthcare providers consciously distance themselves to hide their uncertainty, also contribute to substandard care (Markey et al., 2019). Further, this result focuses strongly on the individual healthcare provider's shortcomings, **overlooking the roles of both the healthcare organisation and the healthcare system** in the provision of substandard care, through inadequate follow-up and support for healthcare providers (Dell'aversana & Bruno, 2021).

As chapter 5 shows, the tasks that the informal carer must undertake to fully organise and provide care contribute to the heavy burden they experience. Thus, it is evident that additional support from professional care is necessary. The next section examines how future healthcare providers can be trained to address this need.

7.1.3 How can future healthcare providers be trained in becoming culturally competent and sensitive healthcare providers?

Chapters 3, 4 and 5 show that cultural awareness and sensitivity are needed to understand inequalities in healthcare, and to reflect on (own) implicit biases and their impact on the provision of care in practice. Chapter 6 builds further on that insight and shows that **healthcare education can increase cultural awareness**, and more specific self-awareness of students. Chapter 6 demonstrates that the developed and implemented educational module was experienced as positive and enriching by the students, so this can be a step towards further training and education to be developed. Current and future cultural competency training must **move beyond merely discussing cultural differences of 'the other'**, and must **focus primarily on self-reflection, self-awareness**, and **knowledge about inequalities, structural inequalities, and racial discrimination in all its forms**.

Since chapters 3, 4 and 5 show that uncaring encounters do occur and are even normalised in daily care practice, **education can also pay attention to uncaring encounters and culturally insensitive care**, and their consequences for the patient. Moreover, research indicates that more attention to the relational aspect of the profession in simulation education can also lead towards increased awareness among students (Červený et al., 2022; Knutsson et al., 2022).

7.1.4 Overarching reflections in relation to the findings

There are 4 themes that occur across the studies in chapters 3 to 6. This concerns caring and uncaring encounters in healthcare, othering and racial discrimination, the optional character of culturally sensitive care and structural gaps in the healthcare system.

Caring en uncaring encounters

Throughout the discussion of the dissertation, the model of caring and uncaring encounters emerged as a prevalent and useful framework for culturally sensitive care. The concept of 'encounter' in relation to the interaction between healthcare provider and patient is discussed in various models and theories, especially from the perspective of the nurse (Holopainen et al., 2019). For this dissertation, Halldorsdottir’s model aligns best with the perception of the patient, informal carer and healthcare provider of both culturally sensitive and culturally insensitive care (Halldorsdottir, 1996). This model shows **a continuum of positive and negative interactions** between the healthcare provider and the patient in a healthcare setting. The model was originally developed to explain the interactions between healthcare providers and oncology patients, and to indicate how the attitude of the healthcare provider influences the patient's condition (Halldorsdottir, 1996, 2008). Caring encounters are characterised by empathy, compassion, and genuine concern for the patient's well-being, fostering trust and a sense of connection. In contrast, uncaring encounters involve disinterest and indifference, insensitivity, and a lack of empathy, leading to feelings of dehumanisation and neglect in patients. This model highlights the impact of healthcare providers' attitude and behaviour on the quality of care and patient outcomes using the metaphor ‘bridge’ and ‘wall’, as seen in figure 3. By emphasizing the importance of the interaction, it provides **a framework for improving patient-provider interaction and overall care quality**.

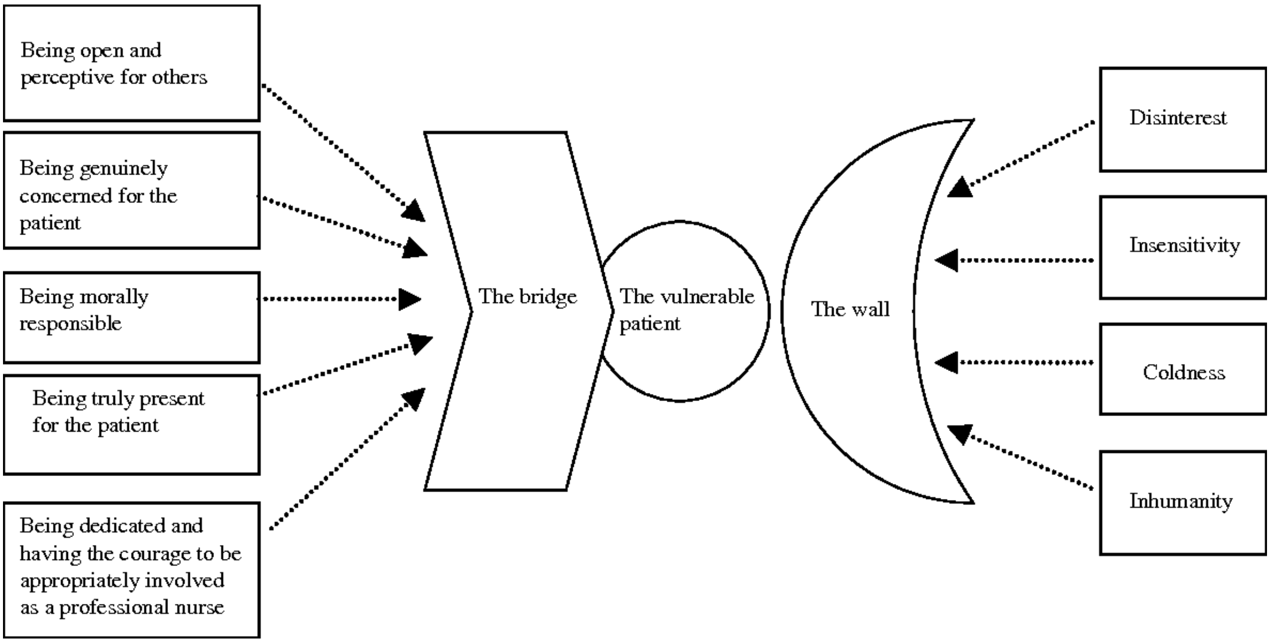

Figure 3: Model of Caring and Uncaring Encounters (Halldorsdottir, 1996)

Chapters 3, 4 and 5 show that **healthcare providers and informal carers report both caring and uncaring encounters** in current daily practice. Disengagement strategies can explain the use of uncaring encounters as a strategy for concealing uncertainty when providing culturally sensitive care (Halldorsdottir, 1996; Markey et al., 2019). Moreover, research has shown that sharing a language is a facilitator for caring encounters and, conversely, speaking a different language can be a reason for uncaring encounters (Söderman et al., 2018). The preference for the task-oriented approach over the relationship-oriented approach, mentioned in chapter 3, also aligns with this model, where the healthcare provider can mask the perceived uncertainty and the uncomfortable feeling of uncaring encounters by referring to a multitude of tasks. Finally, the uncaring encounter can originate in a negative perception and attitude towards 'the other'. Chapters 3, 4 and 5 demonstrate that there is not always a clear difference between an uncaring encounter and implicit or even explicit racist behaviour on the part of the healthcare provider, which are also present in healthcare (Zemouri et al., 2024).

By incorporating the findings from chapters 3, 4, and 5 into the existing model, we develop a comprehensive framework for culturally sensitive and culturally insensitive encounters, as illustrated in Figure 4.

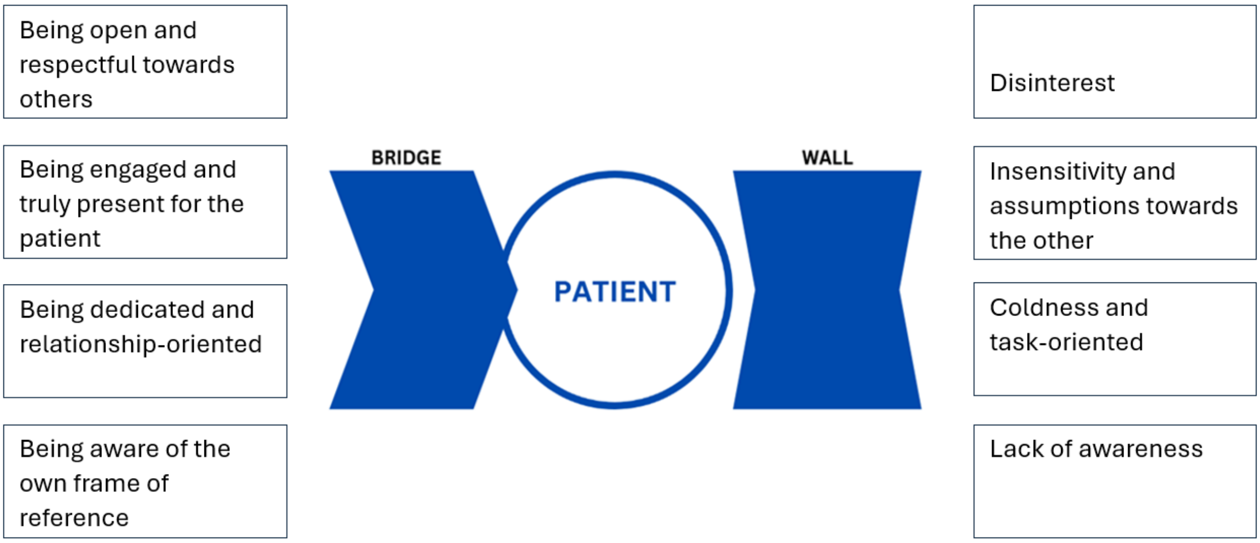

Figure 4: Framework for culturally sensitive and culturally insensitive encounters

If the healthcare provider sees culturally sensitive care as an enrichment and looks at the patient from a positive and open attitude, striving for a care alliance with the informal carer, this attitude is then more in line with the concept of caring encounters and person-oriented care. This interpretation can ensure **more personal appreciation and job satisfaction** for the healthcare provider (Diepen et al., 2020; Iyeke, 2020). In times of mental burden and burnout among healthcare providers, these meaningful relationships can be of great significance for both patient and healthcare provider (Aloisio et al., 2018; Diepen et al., 2020).

The model of caring and uncaring encounters emphasizes the interaction between the patient and healthcare provider. Chapter 4 demonstrates that in culturally sensitive care, it is important not only to focus on the interpersonal level, but also to take into account **the influences of the healthcare organisation (management level) and the healthcare system (policy level)** (Fukui et al., 2021). Both levels are expected to enhance and enable healthcare providers in delivering caring encounters while minimizing uncaring encounters as much as possible. Finally, **healthcare education can play an important role**, in encouraging caring encounters in healthcare students, and by discussing uncaring encounters and its impact of the patient outcome (Halldórsdóttir & Hamrin, 1997). This can be done by giving these relational aspects in patient care a more prominent place in healthcare provider training (e.g. simulation training), by discussing the caring and uncaring sides of the model, and by discussing both culturally sensitive and insensitive care (Knutsson et al., 2022). The positive perspective on culturally sensitive care highlights that diversity can be viewed as an enrichment rather than a problem. Embracing this mindset can motivate healthcare providers to engage in **personal and professional development** in order to adapt healthcare provision to current and future diversity.

Othering and racial discrimination in healthcare

Othering and racial discrimination can be linked to the findings of each study discussed in this dissertation. When othering occurs in healthcare providers behaviour or communication, it happens mostly unconsciously, which is also the case in chapters 3 and 4, and which is also confirmed in other research (Coates, 2022; Hamed et al., 2022). As the findings in chapter 3 show, **‘the other’ is often seen as the stereotypical image** of a Muslim patient, which aligns with the framing in current Western societies (Fadil, 2019; Shaker & Ahmadi, 2022).

Chapter 3 shows that the origin of this othering lies in a **lack of self-awareness** and a lack of insight into one's own frame of reference. One only sees the other as 'cultural' or 'ethnic', without considering one's own position. The positive interpretation of culturally sensitive care shows that self-awareness can be developed and that this has a positive influence on the way people view culturally sensitive care and 'the other'. Moreover, chapter 6 demonstrates that education can play a role in this, by focusing on increasing self-awareness and 'cultural' awareness.

It is without question that othering and racial discrimination are not a part of quality care. However, research points out that white healthcare providers feel uncomfortable talking about racial discrimination (DiAngelo, 2011, 2016) . They experience conversations and discussions about racism as a structural and ongoing polarizing problem (Hamed et al., 2022). This can be explained by the concept of **white fragility**. DiAngelo (2011) argues that for many white people there is little direct or sustained challenge to their own racial understanding. A one-time training on cultural competences may be the only challenge in this context, and these trainings usually do not address issues such as racism or white privilege. White fragility can be described as the inability of white people to cope with the stress associated with issues of skin colour and racism (DiAngelo, 2011). Although racism is experienced as a difficult topic to talk about, the number of **studies on racism in healthcare** has increased significantly since 2018. With this strong rise in research, it is important to mention that most of the studies on this theme come from the US. Only a very limited number of studies were conducted in Europe, mainly in the UK (Hamed et al., 2022; Zemouri et al., 2024). This could be attributed to the 'sensitive and politicised nature of racism in Europe' and the construction of Europe as 'exceptional and anti-racist'. Following the Second World War, the term 'race' was largely excluded from European social, political, and public discourse and was rejected as a scientific category which therefore also influences research on racial exclusion in Europe (Bradby et al., 2019; Hamed et al., 2022). Further, within the context of postcolonialism, it is essential to recognize that the intellectual paradigms which facilitated, justified, and rendered colonisation persist even in current society (Rutazibwa, 2017; Wekker, 2016). Finally, we must consider that these processes take place in a **contemporary context that is strongly opposed to diversity and migration** (Bajomi-Lázár, 2019; Cap, 2017). This is a trend that can be seen throughout Europe, where human rights are questioned, and where the value and importance of migration is denied (Abubakar et al., 2024).

The optional character of culturally sensitive care

The optional character of culturally sensitive care in its implementation is a third finding that emerges as a recurrent theme across all studies in this dissertation. This **non-binding characteristic** becomes particularly clear in the implementation. Chapter 4 demonstrates this issue on every discussed level: the individual healthcare provider, management level, the healthcare system, and policy frameworks. Neither diversity nor culturally sensitive care is prioritised as a strategic goal by policies or organisations, as chapter 4 points out. While culturally sensitive care can be provided, there are no repercussions for neglecting it, and this lack of accountability extends across all levels. Chapter 5 shows that informal carers also encounter this lack of obligation, as their questions go unanswered or ignored without any consequences. In educational settings, culturally sensitive care is addressed through a stand-alone module rather than integrated throughout the entire curriculum, as seen in chapter 6.

Healthcare and education (among other things) are constructed and given shape from the **system of whiteness**. This means that white persons are the main target group for all institutions in this system, and that these institutions de facto do not focus on a diverse group. Whiteness can be described as a system that is linked to a skin colour, to a culture, to a perspective, to a system of power, and also class, to which some individuals are more connected than others (Bonini & Matias, 2021; Essed & Trienekens, 2008). From the system of whiteness, **a focus on diversity becomes optional**. By situating the optional character of culturally sensitive care within the institutional system of whiteness, it becomes clear that the absence of culturally sensitive care and the lack of a diversity perspective in healthcare places a larger responsibility on the institutional stakeholders involved (Mayes, 2020; Mickleborough & Martimianakis, 2021). This includes healthcare organizations, umbrella organizations, and the healthcare system. Due to the organisational lack of support towards healthcare providers in the perspective of culturally sensitive care, as seen in chapter 4, care organisations confirm **the impression of non-importance**. Whiteness as institutional policy in health care and education also hinders the inflow and progression of health care providers of colour, resulting in fewer people of colour becoming health care providers and the system perpetuating itself (Bonini & Matias, 2021). Certain interventions can be made that are aimed at diversity (e.g. 'creating a sense of home' as mentioned in chapter 5), but this always remains of an optional and non-binding character. If institutions sincerely want to focus on diversity, then the entire structure and policy of the organisation must aim towards this (Mayes, 2020). Moreover, education can also play a role in this, by focusing on increasing knowledge about racial exclusion and discrimination in healthcare. Other studies also emphasize the need for anti-racism education at personal and policy levels, starting in nursing programs (Hantke et al., 2022).

Structural gaps in healthcare

A fourth overarching finding are the structural gaps in healthcare system and healthcare offer from the policy level. While aforementioned sections could give the impression that it is the health care provider which shows shortcomings, or fails to deliver culturally sensitive care, I would like to emphasize **the importance of structural, systemic changes**. Both healthcare providers and informal carers noted in chapters 3, 4, and 5 that delivering culturally sensitive care is complicated by gaps in the care offer and the implementation of substandard care practices. Further, this same care offer is the environment in which healthcare provider students find themselves during their internships in healthcare.

In addition, chapter 5 also showed that informal carers perceive a cumulative mental burden because they perform **tasks to bridge the gaps in professional care** (e.g. providing quality care, creating a sense of home, and mediating between and educating healthcare providers). Given the healthcare system with compulsory health insurance and the comprehensive social security network in Belgium, the expectation could be that care would also be fully comprehensible and of high quality. However, the COVID-19 pandemic has exposed the inequalities in this system (Nöstlinger et al., 2022).

Moreover, as demonstrated in chapters 4 and 5, **substandard care provision** is a persistent issue. Even when racial inequalities in care are not considered, certain aspects of care are either not provided, inadequately provided, or lack quality. Research across Europe highlights common barriers to accessing and using healthcare services, including low perceived quality and long waiting times (Palm et al., 2021).

Although the goal is to guarantee equal access to healthcare for all, evidence shows that significant **disparities persist between migrants and non-migrants in accessing healthcare services in Europe** (Lebano et al., 2020). Moreover, chapters 3 and 4 also indicate that patients and informal carers with a migration background are referred less quickly and less often, which systematically promotes inequalities. A system of integrated care could provide an answer to this gap (Hughes et al., 2020; Martens et al., 2022). The role of healthcare organisations and umbrella organisations must be studied further in depth, as they serve as the primary stakeholder for policymakers in shaping the healthcare policy, more so than individual healthcare providers.

Finally, there is **lack of a care offer tailored to the needs of a diverse patient population**. Tailored care goes beyond merely adjusting preconditions. It has been previously noted that organisational modifications (e.g. adjusting the daily schedule or division of tasks to meet individual needs) are also necessary to accommodate a diverse patient population. Furthermore, in healthcare education and training, it is important to consider not only knowledge about inequalities, communication skills, and self-awareness but also an understanding of alternative health explanatory models (culturally and socially defined processes of explaining illness, assigning meanings to symptoms, developing causal attributions, and expressing treatment expectations and outcomes) (Apers et al., 2023).

7.2 Implications and recommendations

The findings discussed above have significant implications for both policy and practice. These implications, along with corresponding recommendations, are detailed below.

7.2.1 Tackle othering, racial discrimination, and structural exclusion in healthcare

First, chapters 3 to 5 and other studies show a spectrum of behaviours that enhance exclusion. These include implicit biases, micro-aggressions, unconscious actions such as 'othering,' culturally insensitive care, and sometimes the cultural incompetence of healthcare providers (Aylward et al., 2021; Baptiste et al., 2020; Hamed et al., 2022; Zemouri et al., 2024). In contrast, healthcare providers often exhibit uncertainty, as demonstrated in chapters 3 and 4, and other studies (Markey et al., 2018; Seeleman, 2014). Therefore, **addressing implicit exclusion and discriminatory behaviour requires a nuanced approach**. On the one hand, it is essential to signal to the excluded person that such behaviour is inappropriate. On the other hand, it is necessary to ensure that the healthcare provider's uncertainty does not increase. More self-awareness and critical awareness in healthcare providers is primarily needed in working with culturally diverse patients and their network, as indicated in chapter 3, 4 and 5. In addition, it is important to further examine these cultural competences, and to also recognize and acknowledge the competences of healthcare providers with a migration background (Apers et al., 2023). Developing cultural competences can be done, as chapter 6 shows, through training that not only focuses on 'the other', but that also allows the healthcare providers to look at themselves and their own frame of reference, and that addresses topics such as inequalities in healthcare, racial discrimination, othering and white privilege (Hamed et al., 2022).

Second, developing awareness among healthcare providers and fostering an atmosphere of openness to safely discuss discriminatory behaviour is achievable only **if this awareness and openness are present at all management levels within the organisation**. Management must take responsibility for cultivating this openness and awareness, engaging all stakeholders through a combination of top-down and bottom-up approaches. During this process, monitoring stakeholder diversity is necessary (Fukui et al., 2021; Sorensen et al., 2017). In addition, healthcare providers must be acknowledged for the competences they possess and develop. If multilingual healthcare providers can be called upon to support a translation, this should not be additional tasks for them, but they should also be acknowledged and rewarded for this task (Harrison et al., 2020).

Third, there is **a need to address and tackle discrimination in a safe way**, and in a manner that is acceptable by all stakeholders, as addressing discrimination can lead to tensions between the parties involved in the discriminatory behaviour (Zemouri et al., 2024). Further, there is a need for more research on racism in healthcare because this is a theme that is still underexposed. Unlike housing and employment, healthcare is often assumed to be free from inequalities. However, each year, Unia – an independent public institution that fights discrimination and promotes equality in Belgium – receives about 30 reports of discrimination in healthcare, which is only the visible part of a much larger problem. In early 2024, Unia began a study on patients' experiences with racial discrimination and its impact on their care, a first study like this in Belgium. This research aims to uncover the underlying structures that perpetuate racism, acknowledging it as a structural problem (Unia, 2024).

Fourth, consideration must be given to implementing educational strategies on culturally sensitive care. Chapters 3 to 6 and other studies indicate that more attention should be given to developing the cultural competence of healthcare providers, with more focus on cultural awareness (Apers et al., 2023; Hamed et al., 2022; Moorley et al., 2020). This should be integrated throughout the entire curriculum, not just taught in a single course, and therefore **all lecturers in healthcare training programs must be trained and supported in developing these competences** (Luukkonen et al., 2023; Jeffreys, 2016; Paric et al., 2021). Education for healthcare providers should reflect current and anticipated patient profiles and societal changes, not past situations. Given that today's society is increasingly diverse due to globalisation, students must be prepared for this reality (Markey et al., 2023). Dealing with diversity should be an essential competency, not an optional module. The focus should include ethnocultural diversity and other aspects of a diverse society (Ochs, 2023). Both student and current healthcare providers, along with management, need to develop cultural competences, emphasizing lifelong learning in a rapidly evolving society. Self-awareness should be a part of this lifelong learning process.

Finally, when structural exclusion in healthcare needs to be tackled, the healthcare system and policy in general must consider **the societal perspective regarding 'the other', migration and racial discrimination** (Bajomi-Lázár, 2019; Cap, 2017; Shaker & Ahmadi, 2022). Postcolonialism, societal changes in Europe after the Second World War and the current sociopolitical climate in Europe shape the current societal perception on diversity and migration (Abubakar et al., 2024; Bradby et al., 2019; Hamed et al., 2022). For policy, no longer using 'us-them' rhetoric and explicitly distancing from othering and racist statements would be a strong signal towards a more inclusive 'us-us' society.

7.2.2 Aim for caring encounters in a proficient healthcare system

First, providing **high-quality personalised care must remain the aim for healthcare providers**. It can be assumed that the aim of all healthcare providers and partners in healthcare provision and healthcare policy is to deliver quality care. Moreover, legislation supports this goal by guaranteeing quality care, as seen in the Patient Rights Act and the Decreet on the Quality of Health and Welfare Facilities (Decreet betreffende de kwaliteit van de gezondheids- en welzijnsvoorzieningen, 2003; Wet betreffende de rechten van de patiënt, 2002). However, chapters 3, 4, and 5, as well as other studies, make it clear that this high-quality care is not always assured. There are experiences of culturally insensitive care, uncaring encounters, and substandard care (Markey et al., 2019; Söderman et al., 2018). Staff shortages and a high workload are often cited as reasons for adopting a more task-oriented approach and leaving behind the relationship-oriented approach in care provision (Markey et al., 2019). However, findings from chapters 3, 4, and 5 suggest that a different interpretation of culturally sensitive care is possible. Healthcare providers can demonstrate engagement and establish meaningful care relationships with patients and informal carers, aiming to provide tailored care that meets the individual needs. By fostering a culture of empathy and cultural sensitivity, healthcare providers can establish trust and provide more personalized care. However, to do this, the healthcare provider needs support from the manager and management of his healthcare organisation.

Second, a **shift in vision is needed from the healthcare organisation to prioritize the relational aspect of care**, while continuing to ensure high standards in other tasks. The healthcare organisation must support healthcare providers in delivering culturally sensitive care, tailored to the needs of a diverse patient group (Akpapuna et al., 2020; Dell’aversana & Bruno, 2021; Van Keer et al., 2020). Further, it is the responsibility of management to create conditions that enable healthcare providers to deliver quality personalised care, including taking on tasks such as coordination and cooperation. Care coordination, or support with coordination (e.g. case managers), can also be beneficial for informal carers, supporting them in their coordinating roles (Smith et al., 2021; Wang et al., 2022). Enhanced collaboration and communication among healthcare providers in an integrated care system can improve outcomes for excluded patients (Antunes & Moreira, 2011; Smith et al., 2021). By working together more effectively, healthcare providers can better support informal carers giving shape to a care alliance to carry the care together, as shown in chapter 5. The organisation should support these efforts by offering professional development opportunities and creating a supportive work environment that values and upholds these principles, to facilitate healthcare providers in providing comprehensive, culturally sensitive, and personalised care to all patients. In the same way as actions at healthcare provider level must be supported by management level, the actions of all actors in healthcare must be supported by the healthcare system and its associated policy.

Third, it is the task of the government that shapes the health system to guarantee all users that the **care provided is high-quality and inclusive**. A consequence of this is facilitating a working environment in which healthcare providers can offer high-quality and inclusive care. This means that limitations in time and staff and economic limitations in healthcare must be examined to see what the basic framework is for providing care in a good way. As described in chapter 1, the policy and implementation of healthcare has not evolved similarly with the developments in the patient's profile. The fragmented healthcare and welfare policy, also fragmented across the different policy levels in Belgium, hinders the evolution and innovation of healthcare (Vandeurzen & Steyaert, 2022). There is a need for an integrated approach for care and welfare, to make the shift from a supply-driven and fragmented care towards a demand-driven and integrated healthcare system (Ellis et al., 2022; Karnati et al., 2020). Addressing structural challenges needs policy intervention such as improving social determinants of health for patient groups who perceive health inequalities (Khatri & Assefa, 2022). This requires a high-level political commitment. Moreover, informal carers must be better supported in providing informal care. Respite care and counselling could be ways to ease their burden. In addition, financial support programs can help provide informal care over a lengthy period, as shown in chapter 5. The support measures for informal carers must be developed in a policy that, based on the idea of deinstitutionalisation of care, values the work of the informal care. Only through better cooperation between formal and informal care, with acknowledgment of the competences in both directions, can the trend of the deinstitutionalisation of care take shape further (Antunes & Moreira, 2011).

Fourth, the exploration of caring and uncaring encounters must be further examined through the education of healthcare providers. It is necessary to provide **opportunities for students to discuss not only caring but also uncaring encounters**. By doing so, students can reflect on these experiences, understand their impact, and learn how to address them both personally and within their internship practice (Knutsson et al., 2022). This reflective practice will help them develop the skills needed to foster caring relationships with patients with the aim to provide culturally sensitive care. Further, healthcare education should promote a culture of continuous improvement and development, and lifelong learning. Workshops, seminars, and interprofessional learning opportunities can facilitate healthcare providers in developing communication skills and self-awareness, as seen in chapter 6.

Finally, both the federal state of Belgium and Flanders have committed to **achieving UN's Sustainable Development Goals**. The 2030 Agenda for Sustainable Development, adopted by all UN Member States in 2015, outlines a collective roadmap for fostering peace, prosperity, and sustainability worldwide. These goals emphasize equitable access to healthcare for all, particularly with the challenges of ageing populations and increasingly diverse societies (WHO, 2024). However, the criteria that Flanders uses to measure the achievement of these objectives do not consider the contemporary exclusion mechanisms in healthcare. If the policy aims to accomplish these Sustainable Development Goals, broader criteria and measurements must be provided.

7.3 Critical reflections and suggestions for future research

This section describes reflections on the methodology and on the terminology used in this study. Further, this section describes underexposed themes and makes suggestions for further research.

7.3.1 Methodological considerations

This section describes considerations on the study design and the positionality of the researcher.

Reflections on the study design

The sample of participants in the studies in chapter 3 and 4 included a combination of student and professional healthcare providers, participating in focus group interviews or individual interviews on a voluntary basis. Having experience in health care (as a job or from an internship) in a diverse city (e.g., Brussels) was an inclusion criterium for all participants. Data collection involved in total eight focus group (FG) interviews (n = 46) and 15 individual in-depth interviews. Participants included general practitioners, nurses, midwives, paramedics and students from nursing, midwifery, and medicine programs. The following tables 6 to 8 give more detailed information about the participants.

Table 7: Focus groups students with internship experience (n=23)

Number of participants in FG	Type	Sex	Mean age	Migration background	Data used in study
6	Student nurses	Female	19 y	None	Chapter 3 & 4
8	Student nurses	Mixed	20y	Mixed	Chapter 3 & 4
5	Student midwives	Female	19y	All	Chapter 3
4	Medical students	Mixed	21Y	Mixed	Chapter 3 & 4

Table 8: Focus groups healthcare professionals (n=23)

Number of participants in FG	Type	Sex	Mean age	Migration background	Data used in study
7	Nurses	Female	36y	None	Chapter 3 & 4
4	Midwives	Female	32y	Mixed	Chapter 3
5	Multidisciplinary geriatric team	Female	32y	Mixed	Chapter 4
7	Intercultural mediators	Female	34y	All	Chapter 4

Table 9: Interviews healthcare professionals (n=15)

Number of interviews	Type	sex	Data used in study
3	General practitioners	male	Chapter 3
1	General practitioner	male	Chapter 3 & 4
4	Social workers	female	Chapter 4
3	Doctor - specialists	1 female, 2 male	Chapter 4
2	Home care nurses	female	Chapter 4
2	Paramedics in a long-term care facility	Female	Chapter 4

Underrepresentation in the participant sample of certain profiles can be possible and might have influenced the results. The studies included healthcare providers and student healthcare providers working in Brussels. Students and healthcare providers in more rural areas could have another perspective and face other challenges in relation to culturally sensitive care. Moreover, the large participation of female participants reflects the current gender distribution in healthcare, but a more balanced gender representation in the sample could provide a broader perspective (Dubois et al., 2020). In addition, including a larger number of participants from different healthcare organisations and different regions would provide a more comprehensive understanding of the implementation of culturally sensitive care across different settings and in different context. Finally, the study in chapter 4 discusses barriers and facilitators only from the healthcare providers' perspective. To have a complete picture, it is necessary to also include insights from management and policy staff. In the studies discussed in chapters 3 and 4, selection bias may have occurred, as all participants voluntarily engaged in a study that was announced on culturally sensitive care. This may have caused an overrepresentation of participants interested in ethnic diversity in care and an underrepresentation of those who are not. Moreover, social desirability might have played a role in focus groups en interviews with healthcare providers, as the healthcare providers and student healthcare providers were all interviewed in their role as (future) healthcare provider, and therefore socially desirable answers might be given about the topic of culturally sensitive care (Seeleman, 2014). Despite this bias, it is interesting to point out that the narrow perception of the concept of culturally sensitive care and the emergence of othering and racial expressions were present throughout the focus groups and interviews. To obtain a more integral perspective, it could be useful to also include a broader sample of healthcare providers, from different disciplines and different contexts. Chapter 5 used composite vignettes to present the results, but vignettes are also a well-researched data collection technique (Gray et al., 2017; Marques & Bispo, 2023). To engage healthcare providers who initially lack interest or even show disinterest in culturally sensitive care, using a vignette can effectively initiate data collection for individual interviews or focus groups (Gray et al., 2017).

To explore different perspectives on culturally sensitive care, it is important to not only involve professionals but also explore the perspective of informal cares. The study in chapter 5 explored the experiences of informal carers, providing dementia care for older first-generation labour migrants. Seventeen individual interviews were conducted with informal carers of Italian and Turkish backgrounds. The participants, 11 women and 6 men, and they were recruited through community networks using purposive sampling. The study in chapter 5 focuses on informal carers as family members of older migrants, implying that all informal carers have a migration-related family history. While the study centers on the informal carers' perspective, it does not specifically detail whether the professional care providers in their narratives have a migration background. Participants rarely discussed or inquired about the ethnicity or migration background of professional care providers. When mentioned, it was typically in situations where there was a shared characteristic, such as a similar migration background. Koehn (2009) highlighted that even when healthcare providers and older persons share the same ethno-cultural background, middle-class values and professional socialisation might prevent the providers from critically examining how race, gender, and class intersect in healthcare delivery (Koehn, 2009). The older persons themselves were not interviewed, resulting in an underrepresentation of the patient’s perspective, as the patients' voices were not included. Despite this, chapter 5 shows valuable insights from the informal carers' experiences.

The educational module discussed in chapter 6 was implemented on a small scale within a single nursing program. It was integrated into a course on specific patient needs, involving 34 second-year nursing students from diverse backgrounds. Expanding this module on a larger scale and incorporating it into different programs across various healthcare disciplines would be recommended (Hamed et al., 2022; Markey et al., 2019; Seeleman, 2014).

Reflections on the positionality of the researcher

My identity as a white female and my role as researcher, teacher, and healthcare provider have played a role in conducting this research.

In the data collection for interviews and focus groups described in chapters 3 and 4, there was a gender alignment with many participants, as most identified as women. Ethnically, the focus groups and interviews of student and professional healthcare providers were diverse, though predominantly composed of white healthcare providers, mirroring my own background. In this way, my profile as researcher closely matched the profile of the participants in these chapters, potentially influencing the data collection.

For the study in chapter 5, the researcher profile, particularly the ethnic-cultural background (e.g. white western female), may have influenced the data collection process where interviews were only conducted with informal carers with a migration background. It should be considered that certain elements from their experiences might have remained unspoken.

In chapter 6, my combined experience in research, healthcare, and education provided the opportunity to combine competences from different roles, which may have had an influence on this study. Specifically, findings from the studies in chapters 3 and 4 informed the design and development of the educational module in chapter 6 (researcher role). This educational module was then delivered to a group of students (teacher role), with continuous reference to healthcare practice (healthcare provider role). From this experience, I strongly recommend an interdisciplinary approach in further developing teaching materials on this theme.

7.3.2 Reflections on the used terminology

This section describes reflections on the terminology used in the studies. More specifically, the concepts of 'persons with a migration background' and 'culturally sensitive care' are discussed.

Terminology related to persons with a migration background

A large variety of definitions and terms exist in literature to describe ethnic cultural differences and ethnic culturally diverse groups. These terms sometimes relate to or represent different historical frameworks. Studies from the US, Canada, and Australia also consider indigenous populations when discussing cultural competence in care (Ahmed et al., 2018; Nguyen et al., 2020; O’Keefe et al., 2021), while in European studies more often is referred to migration (Torres, 2019; Zemouri et al., 2024). Diversity in ethnic groups is sometimes referred to as Culturally and Linguistically Diverse (CALD) populations (Khatri & Assefa, 2022). In other studies the terms ‘black and minority ethnic’ (BME) and ‘black, Asian and minority ethic’ (BAME) are used, where the term ‘minority ethnic’ can be preferred above the term ‘ethnic minority’, because ‘ethnic minority’ may suggest the idea that the group discussed is a minority because of its ethnic nature (Botsford & Harrison Dening, 2015). In US racial categories such as ‘black’ and ‘white’ exist as legal racial categories, while in many European countries this categories are illegal (Hamed et al., 2022). The terms ‘racialized minorities’ and majority groups can be used to describe groups who are subject of racism (Hamed et al., 2022).

In Belgium, culturally sensitive care often focuses on individuals with different ethno-cultural backgrounds, typically linked to immigration, as demonstrated in chapter 3. The term ‘person with a migration background’ is then commonly used, as in the different studies from chapter 3 to 6 in this dissertation. However, this term has limitations, especially at an international level, as already shown above. In addition, the Diverse Elderly Care study found that the migration background can lead to different interpretations by healthcare providers, where the migration background of Italian older adults was sometimes overlooked, and the migration background of

Moroccan and Turkish older adults was overemphasized from a religious perspective (Berdai Chaouni & Claeys, 2021).

Recognizing the richness that diversity brings to our society, it can be interesting to reshape terminology starting with ‘diversity’ and further specify it towards ethno-cultural diversity, gender diversity, diversity in abilities, age diversity, etc.

Terminology related to culturally sensitive care

Throughout the dissertation, the term ‘culturally sensitive care’ is used to describe care provided by a healthcare provider to a patient, both being of a different ethno-cultural background (Uzun & Sevinç, 2015). Although this term is the most commonly used in daily healthcare practice, it has been debated due to its overemphasis on culture (Markey et al., 2017; Seeleman, 2014). Chapter 3 points out that despite the theoretical breadth of the concept of culture, healthcare providers often give it a narrow and stereotypical interpretation, frequently equating it with the patient's religion. The extensive study of this concept in this dissertation may also provide a lever for the adoption of a new term.

As indicated in chapter 1, our society is characterised by diversity, influenced by migration, globalization, and transnationalism. In some contexts, this is referred to as a super-diverse society (Torres, 2019; Vertovec, 2007). Diversity encompasses more than just ethno-cultural diversity, as previously described. It can therefore be suggested to evolve from the concept of 'culture' into 'diverse,' emphasizing the mechanisms of exclusion within diversity. The term should not be interpreted too generally, as in "everyone is diverse," which overlooks exclusion mechanisms, nor should it be interpreted too narrowly, from a stereotypical approach.

The term 'sensitive' describes an attitude of involvement and empathy on the part of the healthcare provider (Sagar, 2012; Shen, 2015). While this is a positive starting point, it is also perceived as optional by healthcare providers, as pointed out in chapters 3, 4, and 5, since there is no consequence if the healthcare provider does not show a sensitive attitude towards the patient. In some studies, the term 'responsive' is used in relation to ‘cultural’ (Markey et al., 2023; O’Keefe et al., 2021; Seeleman, 2014). While 'sensitive' refers to an attitude, 'responsive' involves action and responsibility for that action. This allows a clearer determination of whether the healthcare provider has responded appropriately to a particular situation or to a particular need of the patient. It can therefore be suggested to evolve from 'sensitive' to 'responsive' care.

A side note to these reflections on terminology is that a term remains empty without appropriate interpretation in practice. If diverse-responsive care is proposed as a concept to provide appropriate and person-oriented care to patients with diverse profiles, this concept will also remain empty if no effort is made in practice to measure and tackle exclusion and discrimination for diverse profiles in healthcare.

7.3.3 Reflections on underexposed themes

Three themes were either not highlighted or were given less emphasis in the studies presented in chapters 3 to 6. These themes, briefly explained below, are gender, diversity in the broad sense, and specific healthcare domains.

Gender

In this dissertation gender was not explicitly studied or discussed as a variable influencing the perception of culturally sensitive care. However, gender can shape healthcare providers' perspectives on diversity and the delivery of culturally sensitive care, as research has shown that women and individuals with higher ethnic-cultural empathy are more likely to support diversity initiatives (Cundiff et al., 2009). Moreover, research on medical students' experiences highlights gender stereotypes in medical education. Despite claims of gender neutrality, female and male students express stereotypes, such as women being more nurturing in medicine and surgery being dominated by traits stereotypically associated with men (Lempp & Seale, 2006). This demonstrates the importance of understanding how gender dynamics intersect with cultural empathy in healthcare settings. It should be noted that a majority of participants identified as female, consistent with the healthcare workforce composition (Dubois et al., 2020). Therefore, exploring culturally sensitive care through a gender lens could provide valuable insights. Regarding exclusion and discrimination, it is important to recognize that exclusion can be compounded by intersections such as ethnicity and gender (Aspinall et al., 2021; Karaman & Christian, 2020). So, when perspectives of patients or informal carers are included, it is also important to include the aspect of gender in the research.

Diversity

Chapter 1 indicated that diversity is a broad concept and concerns all differences between people in a society (Vertovec, 2007). This dissertation only focused on diversity by origin or ethno-cultural diversity. In other research ethnic diversity is often discussed in relation to religious diversity, as a global phenomenon (Amin, 2019).

There are other forms of diversity that are not discussed in this work. In chapter 6, the students already indicated that from their perception, diversity should be interpreted from a broader perspective in the educational module, and that, for example, themes such as gender and sexual orientation (referred to as LGBT or LGBTQIA+) should also be discussed. Research shows that persons that are diverse in gender identity and sexual orientation are also often subject inequalities in health. Members of the LGBT community continue to experience health disparities resulting in a poor life quality and reduced health outcomes (Vance, 2019; Whitehead et al., 2016). The uncertainty and the lack of awareness, as discussed in chapter 3, is also seen in research of healthcare providers caring for LGBT patients (Santander-Morillas et al., 2022; Table et al., 2022). Similar as for ethnic-cultural diversity, here is also suggested to provide mandatory education for healthcare providers in order to overcome health inequalities (Lecompte et al., 2021; Santander-Morillas et al., 2022; Vance, 2019). Healthcare education has the aim to increase competences necessary to address LGBT person's needs. Moreover, healthcare staff must have knowledge on LGBT realities, openness and must be able to put certain skills into practice (Gomez Ibañez et al., 2024; Lecompte et al., 2021). A study reported short-term improvement in knowledge, attitudes and practice of healthcare students and professionals with regards to sexual and LGBT-specific healthcare, after a training (Sekoni et al., 2017).

At the intersection of sexual orientation, gender identity and ability, health inequalities are reinforced for LGBTIQA+ people with disability. LGBTIQA+ education for disability services and disability and accessibility education for LGBTIQA+ is suggested (O'Shea et al., 2020). Specifically, for persons with a disability (also a diverse group with specific needs) also more training is suggested to train the healthcare workforce to respect persons with a disability (in this study women with disabilities), to pay attention to their individual preferences, provide non-discriminatory and respectful care, and address stigmatizing attitudes (Matin et al., 2021). Also adolescents and adults with intellectual disabilities and/or autism experience several barriers to accessing and using healthcare services (Doherty et al., 2020).

It can be concluded that there is variation in diversity, yet groups deviating from the norm in one or more aspects of their identity are frequently excluded from healthcare and welfare facilities. Therefore, a broader interpretation of diversity could be considered within the framework of culturally sensitive care.

Specific healthcare domains in relation to culturally sensitive care

Within the broad healthcare system, there are specific domains, such as mental health care or palliative care. Specific patient needs arise in these domains, and specific needs may therefore also exist in relation to culturally sensitive care in for example mental healthcare or palliative care. This was not studied in this study and may be recommended to be explored in further research.

Unlike general health care, where the focus is often on physical health, mental health care requires a different approach and has different treatment methods. The patient's beliefs and exploratory models play a role in the mental health of the patient and individual and group therapy plays a key role in the treatment. It is therefore important to transcend cultural barriers, such as language barriers and differences in beliefs (Apers et al., 2023). In addition, historical events and structural exclusion can also play a role in the need for and use of mental health care. For example, the 600 diverse American Indian/Alaska Native communities have faced historical genocidal practices and ongoing oppression, leading to high rates of mental health and substance use disorders, where under resourced mental health care and various barriers to formal care services consolidate these disparities (O’Keefe et al., 2021). Similarly, Syrian refugees and asylum seekers in Switzerland face multiple barriers to accessing mental healthcare, including language barriers, lack of resources, and cultural differences with the local health system and the healthcare provider (Kiselev et al., 2020). Thus, culturally sensitive care is essential for effectively addressing mental health disparities in diverse populations. It is therefore necessary to also study the implementation of culturally sensitive care in specific healthcare domains, such as mental health care.

With an increasingly ageing population, there will be a rising demand for palliative care, including from older migrants and ethnic minorities (Suurmond et al., 2021). Research indicates that studies are necessary to address racial and ethnic health disparities in palliative care, particularly those addressing complex multilevel factors influencing health disparities (Jones et al., 2021). There is a need for tailored end-of-life-care information towards older adults with a migration background (Demirkapu et al., 2023). Further, research shows that many (future) physicians are unfamiliar with the specific needs of these groups regarding care and communication in palliative settings (Suurmond et al., 2021). In addition, many medical lectures feel unprepared to teach palliative care and culturally sensitive communication to students in a medical education, highlighting a need for courses addressing cross-cultural issues in end-of-life care, integrated into existing course programs and included at all stages of the curriculum (Semlali et al., 2020). Similarly, as in mental health care, it is therefore necessary to also study the implementation of culturally sensitive care in other specific care domains, such as palliative health care.

7.3.4 Suggestions for further research

The studies in chapters 3 and 4 started from healthcare providers who had an interest or involvement in the theme of culturally sensitive care. It would be useful to also include a broader sample of healthcare providers, from different disciplines and different contexts.

Also, more research is needed on discrimination and racism in the healthcare sector. This domain has been understudied in mainland of Europe and Belgium. Recent studies indicate that discrimination and racism do occur in healthcare, and that this needs to be further and more deeply investigated (Hamed et al., 2022; Unia, 2024; Zemouri et al., 2024). Deeper power relationships must also be studied within this, because other research has already indicated that healthcare providers of colour sometimes also experience racism from white patients (Hamed et al., 2022). Instead of studying 'race' and its consequences in society, it would be better to take racialisation processes and exclusion through racism as a starting point for further research (Nazroo et al., 2020).

Further research is necessary to explore the caring and uncaring encounters in daily care practice. It is necessary to investigate what moves a healthcare provider towards the provision of uncaring encounters. A hypothesis could be that an uncaring encounter could be a coping strategy for the healthcare provider to shield themselves from emotional involvement during high work pressure and staffing shortages, but more research is needed in this field.

7.4 Conclusions

Culturally sensitive care is essential; it is not optional, but it is a basic principle in health care provision. It can be implemented in a positive, enriching way, and it should be the standard practice in healthcare and healthcare education. In the current superdiverse society, which includes various identities like ethno-culturally diverse backgrounds, diversity on gender and LGBTQ+, diversity in socio-economic status and abilities, etc., a diverse sensitive approach is necessary to tackle exclusion on every level. Addressing uncaring encounters in healthcare, including in the management level of care organisations and in healthcare education, is necessary.

Implementation of sensitive care must occur at all levels, with the management level taking responsibility towards increasing awareness, leading to the perception that culturally sensitive care is the most obvious choice for healthcare providers in providing care. Accepting the current and future state of society's increasing diversity is necessary. Diversity should be reflected at all levels of an organisation, including in the management. Being competent in diversity should focus on awareness rather than the focus on cultural differences of ‘the other’. Tackling racist and discriminatory behaviour requires awareness of othering, and other forms of racial discrimination. This calls for a clear position against discrimination and racism in healthcare and in society in general, supported by policy. Finally, policy must address the gaps in healthcare services, by providing tailored services for diverse groups and support for informal carers. The current approach is no longer sufficient and there is a need for personalised care to meet diverse and complex care needs.

References

Abubakar, I., Langella, R., & Meda, N. (2024). Europe's anti-migration policies: The need to reverse a trajectory towards death, despair, and destitution. *The Lancet*, *403*(10443), 2465-2467. https://doi.org/10.1016/S0140-6736(24)00922-X

Ahmed, S., Siad, F. M., Manalili, K., Lorenzetti, D. L., Barbosa, T., Lantion, V., Lu, M., Quan, H., & Santana, M.-J. (2018). How to measure cultural competence when evaluating patient-centred care: A scoping review. *BMJ Open*, *8*(7), e021525. https://doi.org/10.1136/bmjopen-2018-021525

Akbulut, N., & Razum, O. (2022). Why Othering should be considered in research on health inequalities: Theoretical perspectives and research needs. *SSM - Population Health*, *20*, 101286. https://doi.org/10.1016/j.ssmph.2022.101286

Akpapuna, M., Choi, E., Johnson, D. A., & Lopez, J. A. (2020). Encouraging Multiculturalism and Diversity within Organizational Behavior Management. *Journal of Organizational Behavior Management*, *40*(3-4), 186-209. https://doi.org/10.1080/01608061.2020.1832014

Aloisio, L. D., Gifford, W. A., McGilton, K. S., Lalonde, M., Estabrooks, C. A., & Squires, J. E. (2018). Individual and organizational predictors of allied healthcare providers' job satisfaction in residential long-term care. *BMC Health Services Research*, *18*(1), 491. https://doi.org/10.1186/s12913-018-3307-3

Amin, S. (2019). Diversity enforces social exclusion: Does exclusion never cease? *Journal of Social Inclusion*, *10*(1), 4. https://doi.org/10.36251/josi.161

Anjorin, O., & Busari, J. O. (2023). Unpacking the Social Constructs of Discrimination, Othering, and Belonging in Medical Schools. *Teaching and Learning in Medicine*, *0*(0), 1-9. https://doi.org/10.1080/10401334.2023.2230211

Antunes, V., & Moreira, J. P. (2011). Approaches to developing integrated care in Europe: A systematic literature review. *Journal of Management & Marketing in Healthcare*, *4*(2), 129-135. https://doi.org/10.1179/175330311X13016677137743

Apers, H., Nöstlinger, C., & Van Praag, L. (2023). Explanatory Models of (Mental) Health Among Sub-Saharan African Migrants in Belgium: A Qualitative Study of Healthcare Professionals' Perceptions and Practices. *Culture, Medicine, and Psychiatry*, *47*(4), 878-897. https://doi.org/10.1007/s11013-023-09816-6

Aspinall, C., Jacobs, S., & Frey, R. (2021). The impact of intersectionality on nursing leadership, empowerment and culture: A case study exploring nurses and managers' perceptions in an acute care hospital in Aotearoa, New Zealand. *Journal of clinical nursing*. https://doi.org/10.1111/jocn.15745

Aylward, B. S., Gal-Szabo, D. E., & Taraman, S. (2021). Racial, Ethnic, and Sociodemographic Disparities in Diagnosis of Children with Autism Spectrum Disorder. *Journal of Developmental and Behavioral Pediatrics*, *42*(8), 682-689. https://doi.org/10.1097/DBP.0000000000000996

Baak, M. (2019). Racism and Othering for South Sudanese heritage students in Australian schools: Is inclusion possible? *International Journal of Inclusive Education*, *23*(2), 125-141. https://doi.org/10.1080/13603116.2018.1426052

Bajomi-Lázár, P. (2019). An anti-migration campaign and its impact on public opinion: The Hungarian case. *European Journal of Communication*, *34*(6), 619-628. https://doi.org/10.1177/0267323119886152

Baptiste, D.-L., Josiah, N. A., Alexander, K. A., Commodore-Mensah, Y., Wilson, P. R., Jacques, K., & Jackson, D. (2020). Racial discrimination in health care: An “us” problem. *Journal of Clinical Nursing*, *29*(23-24), 4415-4417. https://doi.org/10.1111/jocn.15449

Berdai Chaouni, S., & Claeys, A. (2021). *Dementie bij ouderen met een migratieachtergrond*. Garant / Maklu.

Blix, B., & Munkejord, M.-C. (2022). Indigenous Sami Family Caregivers’ Experiences With Accessing and Collaborating With Municipal Health and Care Services. *Global Qualitative Nursing Research*, *9*. https://doi.org/10.1177/23333936221123333

Bonini, S. M., & Matias, C. E. (2021). The impact of Whiteness on the education of nurses. *Journal of Professional Nursing*, *37*(3), 620-625. https://doi.org/10.1016/j.profnurs.2021.02.009

Botsford, J., & Harrison Dening, K. (Red.). (2015). *Dementia, culture, and ethnicity: Issues for all*. Jessica Kingsley Publishers.

Bradby, H., Thapar-Björkert, S., Hamed, S., & Ahlberg, B. M. (2019). Undoing the unspeakable: Researching racism in Swedish healthcare using a participatory process to build dialogue. *Health Research Policy and Systems*, *17*(1), 43. https://doi.org/10.1186/s12961-019-0443-0

Brons, L. (2015). Othering, an analysis. *Transcience. A Journal of Global Studies*, *6*(1), 69-90.

Cap, P. (2017). Immigration and Anti-migration Discourses: The Early Rhetoric of Brexit. In P. Cap (Red.), *The Language of Fear: Communicating Threat in Public Discourse* (pp. 67-79). Palgrave Macmillan UK. https://doi.org/10.1057/978-1-137-59731-1_6

Červený, M., Kratochvílová, I., Hellerová, V., & Tóthová, V. (2022). Methods of increasing cultural competence in nurses working in clinical practice: A scoping review of literature 2011-2021. *Frontiers in Psychology*, *13*, 936181. https://doi.org/10.3389/fpsyg.2022.936181

Coates, R. D. (2022). Othering. In *Framing Social Theory*. Routledge.

Cundiff, N. L., Nadler, J. T., & Swan, A. (2009). The Influence of Cultural Empathy and Gender on Perceptions of Diversity Programs. *Journal of Leadership & Organizational Studies*, *16*(1), 97-110. https://doi.org/10.1177/1548051809334193

Decreet betreffende de kwaliteit van de gezondheids- en welzijnsvoorzieningen (2003). https://codex.vlaanderen.be/Portals/Codex/documenten/1011700.html

Dell’aversana, G., & Bruno, A. (2021). Supporting Cultural Competence: Practices of Managers and Line Workers in a Health Service. *TPM: Testing, Psychometrics, Methodology in Applied Psychology*, *28*(1), 65-81. https://doi.org/10.4473/TPM28.1.5

Demirkapu, H., Van de Block, L., De Maesschalck, S., De Vleminck, A., Colak, F. Z., & Devroey, D. (2023). Advance care planning among older adults with a Turkish background and palliative care needs: A qualitative interview study. *British Journal of General Practice*, *73*(suppl 1). https://doi.org/10.3399/bjgp23X734001

DiAngelo, R. (2011). White Fragility. *The International Journal of Critical Pedagogy*, *3*(3), Article 3. http://libjournal.uncg.edu/ijcp/article/view/249

DiAngelo, R. (2016). *What does it mean to be white? Developing white racial literacy* (Revised edition). Peter Lang.

Diepen, C. van, Fors, A., Ekman, I., & Hensing, G. (2020). Association between person-centred care and healthcare providers’ job satisfaction and work-related health: A scoping review. *BMJ Open*, *10*(12), e042658. https://doi.org/10.1136/bmjopen-2020-042658

Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: An integrative review. *BJGP Open*, *4*(3). https://doi.org/10.3399/bjgpopen20X101030

Dubois, H., Leončikas, T., Molinuevo, D., & Wilkens, M. (2020). *Long-term care workforce: Employment and working conditions.* European Foundation for the Improvement of Living and Working Conditions. https://data.europa.eu/doi/10.2806/36712

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., van Hout, H., & Broese van Groenou, M. I. (2022). Accessibility of health care experienced by persons with dementia from ethnic minority groups and formal and informal caregivers: A scoping review of European literature. *Dementia (London, England)*, *21*(2), 677-700. https://doi.org/10.1177/14713012211055307

Duran-Kiraç, G., Uysal-Bozkir, Ö., Uittenbroek, R., van Hout, H., & Broese van Groenou, M. I. (2023). Informal caregiver and nurse perceptions of access to culturally appropriate health care for ethnic minority persons with dementia: A qualitative study. *Journal of Advanced Nursing (John Wiley & Sons, Inc.)*, *79*(8), 3002-3014. https://doi.org/10.1111/jan.15687

Ellis, D. M., Draheim, A. A., & Anderson, P. L. (2022). Culturally adapted digital mental health interventions for ethnic/racial minorities: A systematic review and meta-analysis. *Journal of Consulting and Clinical Psychology*, *90*(10), 717-733. https://doi.org/10.1037/ccp0000759

Essed, P., & Trienekens, S. (2008). 'Who wants to feel white?' Race, Dutch culture and contested identities. *Ethnic and Racial Studies*, *31*(1), 52-72. https://doi.org/10.1080/01419870701538885

Fadil, N. (2019). The Anthropology of Islam in Europe: A Double Epistemological Impasse. *Annual Review of Anthropology*, *48*(1), 117-132. https://doi.org/10.1146/annurev-anthro-102218-011353

Fukui, S., Salyers, M. P., Morse, G., & Rollins, A. L. (2021). Factors that affect quality of care among mental health providers: Focusing on job stress and resources. *Psychiatric Rehabilitation Journal*, *44*(3), 204-211. https://doi.org/10.1037/prj0000469

Gomez Ibañez, R., Leyva-Moral, J. M., Cruzado-Reyes, A., Platero Méndez, R. L., Granel, N., & Watson-Badia, C. E. (2024). Describing Non-Binary People's Encounters with the Healthcare System: A Qualitative Study in Catalonia (Spain). *Archives of sexual behavior*, *53*(5), 1957-1967. https://doi.org/10.1007/s10508-024-02849-x

Gray, D., Royall, B., & Malson, H. (2017). *Hypothetically speaking: Using vignettes as a stand-alone qualitative method*. https://uwe-repository.worktribe.com/output/835120/hypothetically-speaking-using-vignettes-as-a-stand-alone-qualitative-method

Halldorsdottir, S. (1996). *Caring and Uncaring Encounters in Nursing and Health Care—Developing a Theory*.

Halldorsdottir, S. (2008). The dynamics of the nurse–patient relationship: Introduction of a synthesized theory from the patient's perspective. *Scandinavian Journal of Caring Sciences*, *22*(4), 643-652. https://doi.org/10.1111/j.1471-6712.2007.00568.x

Halldórsdóttir, S., & Hamrin, E. (1997). Caring and uncaring encounters within nursing and health care from the cancer patient's perspective. *Cancer Nursing*, *20*(2), 120-128. https://doi.org/10.1097/00002820-199704000-00007

Hamed, S., Bradby, H., Ahlberg, B. M., & Thapar-Björkert, S. (2022). Racism in healthcare: A scoping review. *BMC Public Health*, *22*(1), 988. https://doi.org/10.1186/s12889-022-13122-y

Hantke, S., St. Denis, V., & Graham, H. (2022). Racism and antiracism in nursing education: Confronting the problem of whiteness. *BMC Nursing*, *21*(1), 146. https://doi.org/10.1186/s12912-022-00929-8

Harrison, R., Walton, M., Chitkara, U., Manias, E., Chauhan, A., Latanik, M., & Leone, D. (2020). Beyond translation: Engaging with culturally and linguistically diverse consumers. *Health expectations : an international journal of public participation in health care and health policy*, *23*(1), 159-168. https://doi.org/10.1111/hex.12984

Hassen, N., Lofters, A., Michael, S., Mall, A., Pinto, A. D., & Rackal, J. (2021). Implementing Anti-Racism Interventions in Healthcare Settings: A Scoping Review. *International Journal of Environmental Research and Public Health*, *18*(6), Article 6. https://doi.org/10.3390/ijerph18062993

Helbling, M. (2012). Islamophobia in the West. *Measuring and Explaining Individual Attitudes*.

Holopainen, G., Nyström, L., & Kasén, A. (2019). The caring encounter in nursing. *Nursing Ethics*, *26*(1), 7-16. https://doi.org/10.1177/0969733016687161

Hughes, G., Shaw, S. E., & Greenhalgh, T. (2020). Rethinking Integrated Care: A Systematic Hermeneutic Review of the Literature on Integrated Care Strategies and Concepts. *The Milbank Quarterly*, *98*(2), 446-492. https://doi.org/10.1111/1468-0009.12459

Iyeke, P. (2020). Job satisfaction as a correlate of empathic behaviour among health care providers towards their patients. *International Journal of Healthcare*, *7*(1), 29. https://doi.org/10.5430/ijh.v7n1p29

Jones, T., Luth, E. A., Lin, S.-Y., & Brody, A. A. (2021). Advance Care Planning, Palliative Care, and End-of-life Care Interventions for Racial and Ethnic Underrepresented Groups: A Systematic Review. *Journal of Pain and Symptom Management*, *62*(3), e248-e260. https://doi.org/10.1016/j.jpainsymman.2021.04.025

Jutlla, K. (2015). The impact of migration experiences and migration identities on the experiences of services and caring for a family member with dementia for Sikhs living in Wolverhampton, UK. *Ageing & Society*, *35*(5), 1032-1054. https://doi.org/10.1017/S0144686X14000658

Karaman, N., & Christian, M. (2020). "My Hijab Is Like My Skin Color": Muslim Women Students, Racialization, and Intersectionality. *Sociology of Race and Ethnicity*, *6*(4), 517-532. https://doi.org/10.1177/2332649220903740

Karnati, S. A., Wee, A., Shirke, M. M., & Harky, A. (2020). Racial disparities and cardiovascular disease: One size fits all approach? *Journal of Cardiac Surgery*, *35*(12), 3530-3538. https://doi.org/10.1111/jocs.15047

Khatri, R. B., & Assefa, Y. (2022). Access to health services among culturally and linguistically diverse populations in the Australian universal health care system: Issues and challenges. *BMC Public Health*, *22*(1), 880. https://doi.org/10.1186/s12889-022-13256-z

Kiselev, N., Pfaltz, M., Haas, F., Schick, M., Kappen, M., Sijbrandij, M., De Graaff, A. M., Bird, M., Hansen, P., Ventevogel, P., Fuhr, D. C., Schnyder, U., & Morina, N. (2020). Structural and socio-cultural barriers to accessing mental healthcare among Syrian refugees and asylum seekers in Switzerland. *European Journal of Psychotraumatology*, *11*(1), 1717825. https://doi.org/10.1080/20008198.2020.1717825

Knutsson, S., Axelsson, J., & Lindqvist, G. (2022). An application of the caritative caring approach – nursing students' experiences of practising caring and uncaring encounters by simulation at a clinical training centre. *International Journal of Qualitative Studies on Health and Well-being*, *17*(1), 2100610. https://doi.org/10.1080/17482631.2022.2100610

Koehn, S. (2009). Negotiating candidacy: Ethnic minority seniors' access to care. *Ageing and society*, *29*(4), 585-608. https://doi.org/10.1017/S0144686X08007952

Lebano, A., Hamed, S., Bradby, H., Gil-Salmerón, A., Durá-Ferrandis, E., Garcés-Ferrer, J., Azzedine, F., Riza, E., Karnaki, P., Zota, D., & Linos, A. (2020). Migrants' and refugees' health status and healthcare in Europe: A scoping literature review. *BMC Public Health*, *20*(1), 1039. https://doi.org/10.1186/s12889-020-08749-8

Lecompte, M., Ducharme, J., Beauchamp, J., & Couture, M. (2021). Inclusive Practices toward LGBT Older Adults in Healthcare and Social Services: A Scoping Review of Quantitative and Qualitative Evidence. *Clinical Gerontologist*, *44*(3), 210-221. https://doi.org/10.1080/07317115.2020.1862946

Lempp, H., & Seale, C. (2006). Medical students' perceptions in relation to ethnicity and gender: A qualitative study. *BMC Medical Education*, *6*(1), 17. https://doi.org/10.1186/1472-6920-6-17

Luukkonen, A.-L., Kuivila, H., Kaarlela, V., Koskenranta, M., Kaučič, B. M., Riklikiene, O., Vizcaya-Moreno, F., Pérez-Cañaveras, R. M., Filej, B., Oikarainen, A., Kääriäinen, M., & Mikkonen, K. (2023). Mentors' cultural competence at mentoring culturally and linguistically diverse nursing students in clinical practice: An international cross-sectional study. *Nurse Education in Practice*, *70*, 103658. https://doi.org/10.1016/j.nepr.2023.103658

Marianne R. Jeffreys, E., RN. (2016). *Teaching Cultural Competence in Nursing and Health Care: Inquiry, Action, and Innovation: Vol. Third edition*. Springer Publishing Company. https://search.ebscohost.com/login.aspx?direct=true&db=e000xww&AN=1104182&lang=nl&site=eds-live&scope=site&authtype=sso&custid=s3945784

Markey, K., Macfarlane, A., & Manning, M. (2023). Time to re-envisage culturally responsive care: Intersection of participatory health research and implementation science. *Journal of Advanced Nursing*, *79*, n/a-n/a. https://doi.org/10.1111/jan.15821

Markey, K., & Tilki, M. (2007). Racism in nursing education: A reflective journey. *British journal of nursing (Mark Allen Publishing)*, *16*, 390-393. https://doi.org/10.12968/bjon.2007.16.7.23221

Markey, K., Tilki, M., & Taylor, G. (2017). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds. *Journal of Clinical Nursing*, n/a-n/a. https://doi.org/10.1111/jocn.13926

Markey, K., Tilki, M., & Taylor, G. (2018). Understanding nurses' concerns when caring for patients from diverse cultural and ethnic backgrounds. *Journal of Clinical Nursing (John Wiley & Sons, Inc.)*, *27*(1-2), Article 1-2. https://doi.org/10.1111/jocn.13926

Markey, K., Tilki, M., & Taylor, G. (2019). Resigned indifference: An explanation of gaps in care for culturally and linguistically diverse patients'. *Journal of Nursing Management (John Wiley & Sons, Inc.)*, *27*(7), Article 7. https://doi.org/10.1111/jonm.12830

Marques Nascimento Macêdo, N. M., & Bispo, M. de S. (2023). Qualitative Vignettes Drawing on Real Cases as Method in Organizational Research. *Canadian Journal of Administrative Sciences / Revue Canadienne Des Sciences de l'Administration*, *40*(2), 188-198. https://doi.org/10.1002/cjas.1692

Martens, M., Danhieux, K., Van Belle, S., Wouters, E., Van Damme, W., Remmen, R., Anthierens, S., & Van Olmen, J. (2022). Integration or Fragmentation of Health Care? Examining Policies and Politics in a Belgian Case Study. *International Journal of Health Policy and Management*, *11*(9), 1668-1681. https://doi.org/10.34172/ijhpm.2021.58

Matin, B. K., Williamson, H. J., Karyani, A. K., Rezaei, S., Soofi, M., & Soltani, S. (2021). Barriers in access to healthcare for women with disabilities: A systematic review in qualitative studies. *BMC Women's Health*, *21*(1), 44. https://doi.org/10.1186/s12905-021-01189-5

Mayes, C. (2020). White Medicine, White Ethics: On the Historical Formation of Racism in Australian Healthcare. *Journal of Australian Studies*, *44*(3), 287-302. https://doi.org/10.1080/14443058.2020.1796754

Mazaheri, M., Mscn, B., Sunvisson, H., Phd, R., Nikbakht Nasrabadi, A., Bscn, N., Phd, M., Sadat, M., Bscn, M., Emami, A., & Rnt, R. (2011). Bearing witness to life narratives: Iranian immigrant experiences of having a family member with dementia. *Diversity in Health and Care*, 19-28.

Mickleborough, T. O., & Martimianakis, M. A. (Tina). (2021). (Re)producing "Whiteness" in Health Care: A Spatial Analysis of the Critical Literature on the Integration of Internationally Educated Health Care Professionals in the Canadian Workforce. *Academic Medicine*, *96*(11S), S31. https://doi.org/10.1097/ACM.0000000000004262

Mollah, T. N., Antoniades, J., Lafeer, F. I., & Brijnath, B. (2018). How do mental health practitioners operationalise cultural competency in everyday practice? A qualitative analysis. *BMC Health Services Research*, *18*(1), 480. https://doi.org/10.1186/s12913-018-3296-2

Moorley, C., Darbyshire, P., Serrant, L., Mohamed, J., Ali, P., & De Souza, R. (2020). "Dismantling structural racism: Nursing must not be caught on the wrong side of history". *Journal of Advanced Nursing*, *76*(10), 2450-2453. https://doi.org/10.1111/jan.14469

Nazroo, J. Y., Bhui, K. S., & Rhodes, J. (2020). Where next for understanding race/ethnic inequalities in severe mental illness? Structural, interpersonal and institutional racism. *Sociology of Health & Illness*, *42*(2), 262-276. https://doi.org/10.1111/1467-9566.13001

Nguyen, N. H., Subhan, F. B., Williams, K., & Chan, C. B. (2020). Barriers and Mitigating Strategies to Healthcare Access in Indigenous Communities of Canada: A Narrative Review. *Healthcare*, *8*(2), Article 2. https://doi.org/10.3390/healthcare8020112

Nöstlinger, C., Van Landeghem, E., Vanhamel, J., Rotsaert, A., Manirankunda, L., Ddungu, C., Reyniers, T., Katsuva, D., Vercruyssen, J., Dielen, S., & Meudec, M. (2022). COVID-19 as a social disease: Qualitative analysis of COVID-19 prevention needs, impact of control measures and community responses among racialized/ethnic minorities in Antwerp, Belgium. *International Journal for Equity in Health*, *21*(1), 67. https://doi.org/10.1186/s12939-022-01672-x

Ochs, J. H. (2023). Addressing health disparities by addressing structural racism and implicit bias in nursing education. *Nurse Education Today*, *121*, 105670. https://doi.org/10.1016/j.nedt.2022.105670

O'Keefe, V. M., Cwik, M. F., Haroz, E. E., & Barlow, A. (2021). Increasing culturally responsive care and mental health equity with indigenous community mental health workers. *Psychological Services*, *18*(1), 84-92. https://doi.org/10.1037/ser0000358

O'Shea, A., Latham, J. R., McNair, R., Despott, N., Rose, M., Mountford, R., & Frawley, P. (2020). Experiences of LGBTIQA+ People with Disability in Healthcare and Community Services: Towards Embracing Multiple Identities. *International Journal of Environmental Research and Public Health*, *17*(21), Article 21. https://doi.org/10.3390/ijerph17218080

Palm, W., Webb, E., Hernández-Quevedo, C., Scarpetti, G., Lessof, S., Siciliani, L., & van Ginneken, E. (2021). Gaps in coverage and access in the European Union. *Health Policy*, *125*(3), 341-350. https://doi.org/10.1016/j.healthpol.2020.12.011

Paric, M., Kaihlanen, A.-M., Heponiemi, T., & Czabanowska, K. (2021). Nurse teacher's perceptions on teaching cultural competence to students in Finland: A descriptive qualitative study. *Nurse education today*, *99*, 104787. https://doi.org/10.1016/j.nedt.2021.104787

Pérez Huber, L., & Solorzano, D. G. (2015). Racial microaggressions as a tool for critical race research. *Race Ethnicity and Education*, *18*(3), 297-320. https://doi.org/10.1080/13613324.2014.994173

Rutazibwa, O. U. (2017). *Het einde van de witte wereld. Een dekoloniaal manifest*. Epo, Uitgeverij.

Sagar, P. (2012). *Transcultural Nursing Theory and Models: Application in Nursing Education, Practice, and Administration (Springer, 2012)*.

Sagbakken, M., Spilker, R. S., & Nielsen, T. R. (2018). Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC Health Services Research*, *18*(1), 910. https://doi.org/10.1186/s12913-018-3720-7

Santander-Morillas, K., Leyva-Moral, J. M., Villar-Salgueiro, M., Aguayo-González, M., Téllez-Velasco, D., Granel-Giménez, N., & Gómez-Ibáñez, R. (2022). TRANSALUD: A qualitative study of the healthcare experiences of transgender people in Barcelona (Spain). *PloS one*, *17*(8 August). https://doi.org/10.1371/journal.pone.0271484

Schouten, B. C., Manthey, L., & Scarvaglieri, C. (2023). Teaching intercultural communication skills in healthcare to improve care for culturally and linguistically diverse patients. *Patient Education and Counseling*, *115*, 107890. https://doi.org/10.1016/j.pec.2023.107890

Seeleman, M. C. (2014). *Cultural competence and diversity responsiveness: How to make a difference in healthcare?* Universiteit van Amsterdam.

Sekoni, A. O., Gale, N. K., Manga-Atangana, B., Bhadhuri, A., & Jolly, K. (2017). The effects of educational curricula and training on LGBT-specific health issues for healthcare students and professionals: A mixed-method systematic review. *Journal of the International AIDS Society*, *20*(1), 21624. https://doi.org/10.7448/IAS.20.1.21624

Semlali, I., Tamches, E., Singy, P., & Weber, O. (2020). Introducing cross-cultural education in palliative care: Focus groups with experts on practical strategies. *BMC Palliative Care*, *19*(1), 171. https://doi.org/10.1186/s12904-020-00678-y

Shaker, R., & Ahmadi, D. (2022). Everyday embodied othering experiences of young Muslims in the Netherlands. *Journal of Ethnic and Migration Studies*, *48*(19), 4567-4585. https://doi.org/10.1080/1369183X.2022.2096577

Shen, Z. (2015). Cultural Competence Models and Cultural Competence Assessment Instruments in Nursing: A Literature Review. *Journal of Transcultural Nursing*, *26*(3), Article 3.

Shrestha, S., Arora, S., Hunter, A., & Debesay, J. (2023). Changing dynamics of caregiving: A meta-ethnography study of informal caregivers' experiences with older immigrant family members in Europe. *BMC Health Services Research*, *23*(1), 1-18. https://doi.org/10.1186/s12913-023-09023-4

Smith, R., Martin, A., Wright, T., Hulbert, S., & Hatzidimitriadou, E. (2021). Integrated dementia care: A qualitative evidence synthesis of the experiences of people living with dementia, informal carers and healthcare professionals. *Archives of Gerontology and Geriatrics*, *97*, 104471. https://doi.org/10.1016/j.archger.2021.104471

Söderman, M., Rosendahl, S., & Sällström, C. (2018). Caring and Uncaring Encounters between Assistant Nurses and Immigrants with Dementia Symptoms in Two Group Homes in Sweden-an Observational Study. *Journal of Cross-Cultural Gerontology*, *33*(3), 299-317. https://doi.org/10.1007/s10823-018-9351-y

Sorensen, J., Norredam, M., Dogra, N., Essink-Bot, M.-L., Suurmond, J., & Krasnik, A. (2017). Enhancing cultural competence in medical education. *International Journal of Medical Education*, *8*, 28-30. https://doi.org/10.5116/ijme.587a.0333

Stenberg, J., & Hjelm, K. (2023). Migrant informal caregiver perceptions and experiences of caring for a family member with dementia: A systematic review and thematic synthesis. *Journal of Clinical Nursing*, *32*(9-10), 2178-2192. https://doi.org/10.1111/jocn.16390

Suurmond, J., Lantinga, K., de Voogd, X., Oueslati, R., Boland, G., & van den Muijsenbergh, M. (2021). Twelve tips to teach culturally sensitive palliative care. *Medical Teacher*, *43*(7), 845-850. https://doi.org/10.1080/0142159X.2020.1832650

Table, B., Tronstad, L. D., & Kearns, K. (2022). 'Anything is helpful': Examining tensions and barriers towards a more LGBT-inclusive healthcare organization in the United States. *Journal of Applied Communication Research*, *50*(4), 382-401. https://doi.org/10.1080/00909882.2021.1991582

Torres, S. (2019). *Ethnicity and Old Age—Expanding our Imagination*. Policy Press. https://policy.bristoluniversitypress.co.uk/ethnicity-and-old-age

Unia. (2024, februari 29). *Racisme in de gezondheidszorg*. Unia. https://www.unia.be/nl/artikels/racisme-en-geneeskundige-praktijk

Uzun, Ö., & Sevinç, S. (2015). The relationship between cultural sensitivity and perceived stress among nurses working with foreign patients. *Journal of Clinical Nursing*, *24*(23-24), Article 23-24. https://doi.org/10.1111/jocn.12982

Van Keer, R.-L., Deschepper, R., Huyghens, L., & Bilsen, J. (2020). Preventing Conflicts Between Nurses and Families of a Multi-ethnic Patient Population During Critical Medical Situations in a Hospital. *Journal of Transcultural Nursing*, *31*(3), 250-256. https://doi.org/10.1177/1043659619859049

Vance, H. (2019). Healthcare of the LGBT Community. *Kentucky Journal of Undergraduate Scholarship (KJUS)*, *3*(1). https://encompass.eku.edu/kjus/vol3/iss1/10

Vandeurzen, J., & Steyaert, S. (2022). *Geïntegreerde zorg: Werken aan samenwerken* (1ste dr.). Lannoo Campus.

Vertovec, S. (2007). Super-diversity and its implications. *Ethnic and Racial Studies*, *30*(6), 1024-1054. https://doi.org/10.1080/01419870701599465

Wang, N., Chen, J., Chen, W., Shi, Z., Yang, H., Liu, P., Wei, X., Dong, X., Wang, C., Mao, L., & Li, X. (2022). The effectiveness of case management for cancer patients: An umbrella review. *BMC Health Services Research*, *22*(1), 1247. https://doi.org/10.1186/s12913-022-08610-1

Wekker, G. (2016). *White Innocence: Paradoxes of Colonialism and Race*. Duke University Press.

Wet betreffende de rechten van de patiënt., Pub. L. No. 2002022737 (2002). https://www.ejustice.just.fgov.be/cgi_loi/change_lg.pl?language=nl&la=N&cn=2002082245&table_name=wet#list-link-lien_2

Whitehead, J., Shaver, J., & Stephenson, R. (2016). Outness, Stigma, and Primary Health Care Utilization among Rural LGBT Populations. *PLOS ONE*, *11*(1), e0146139. https://doi.org/10.1371/journal.pone.0146139

Woodward, K. (2018). Concepts of identity and difference. In *A Museum Studies Approach to Heritage* (pp. 429-440). https://doi.org/10.4324/9781315668505-34

Zemouri, C., Kassi, A. N., Oñate, W. A. de, Çoban, G., & Kissi, A. (2024). Exploring discrimination and racism in healthcare: A qualitative phenomenology study of Dutch persons with migration backgrounds. *BMJ Open*, *14*(6), e082481. https://doi.org/10.1136/bmjopen-2023-082481

Summary

This dissertation explores the theme of culturally sensitive care, studying it from the perspectives of both healthcare providers and informal carers. The exploration of these viewpoints leads to the development, implementation, and evaluation of an educational module designed to increase cultural awareness among nursing students.

Several demographic and societal trends (e.g., ageing population with increased age-related conditions, a changed patient position, and increased diversity among patients) have reshaped the profile of those needing care in Belgium, presenting new challenges and opportunities for healthcare (Torres, 2019). Current fragmented and uniform care models have reached its limitations, advocating for more integrated and culturally sensitive care solutions (Wickramage et al., 2018). Culturally sensitive care can be proposed as a solution to address challenges and inequalities in healthcare. However, its implementation is challenged (Markey et al., 2018). Culturally sensitive care is an approach used when patient and healthcare provider from different ethnic and cultural backgrounds interact, seeking to build a quality care relationship (Uzun & Sevinç, 2015; Young & Guo, 2020). However, research shows that healthcare professionals feel insecure and have hesitations concerning the concept of culturally sensitive care (Markey et al., 2018; Roberts et al., 2007; Suurmond et al., 2010). In addition, implementing culturally sensitive care faces various challenges across individual, interpersonal, organisational, and systemic levels (Eleri Jones et al., 2017; Scheppers et al., 2006; Suurmond et al., 2016).

Three research gaps were identified and translated in three research questions:

1. How do healthcare providers define, perceive, and deliver culturally sensitive care?
2. How do informal carers of patients with a migration background experience the professional care they receive?
3. How can future healthcare providers be trained in becoming culturally competent and sensitive healthcare providers?

This dissertation used different qualitative research methods to address the research questions. For the first question, data collection involved in total 8 focus group interviews (n = 46) and 15 individual in-depth interviews with professional and student healthcare providers (e.g. nurses, physicians). For the second question, 17 individual in-depth interviews were conducted with informal carers of Italian and Turkish backgrounds (11 women and 6 men). The third question involved developing, implementing, and evaluating a 4-hour intervention in a bachelor nursing program, involving 34 second-year nursing students through curriculum mapping, focus group interviews, and post-intervention surveys.

The findings of the first research question (chapters 3 and 4) indicate that most healthcare providers have a narrow, stereotypical understanding of culturally sensitive care, seeing it as a checklist of practical actions rather than an empathetic approach. This perspective, shaped by a static interpretation of 'culture,' often reduces it to religious practices, particularly those of Muslim patients, highlighting a concept of othering and a lack of awareness about implicit biases and providers' own cultural frames of reference. Consequently, culturally insensitive care and discriminatory behaviour can arise. Healthcare providers view culturally sensitive care as challenging, requiring more effort and time, and while they recognize the need for greater

cultural knowledge, they make little effort to gain it, leading to uncertainty and reliance on assumptions. Although some healthcare providers approach culturally sensitive care from a relationship-oriented perspective and see it as enriching, most individual providers and organizations treat it as unimportant and optional. Initiatives towards culturally sensitive care are often personal rather than organizational mandates, with a noticeable lack of leadership from management in its implementation.

The findings of the second research question (chapter 5) show that informal carers of older persons with dementia and a migration background are seeking professional help to provide the best possible care. Being an informal carer today involves many tasks. Informal carers seek to create a sense of home, using familiar meals, language, and environment to offer personalized care, especially since standard care often lacks cultural sensitivity. Despite some healthcare providers offering tailored care, it is not structural. Moreover, cold-hearted and substandard care is experienced. These negative encounters, marked by disinterest and insensitivity, reflect broader issues in the healthcare system, including inadequate support for providers. Informal carers experience an increasing burden as they try to bridge these gaps, making their role even more challenging.

The third research question (chapter 6) builds on previous insights, showing that healthcare education can increase nursing students' cultural and self-awareness. Findings demonstrate the positive impact of a developed educational module, suggesting it as a basis for further training. Current and future cultural competency training needs to focus on self-reflection, self-awareness, and understanding inequalities and discrimination. The model of caring and uncaring encounters, discussed previously, is not integrated into healthcare education, which emphasizes technical skills. Education needs to address these and their impact on patients. Simulation education, emphasizing relational aspects, can enhance student awareness.

Four themes occur across all studies in this dissertation: caring and uncaring encounters in healthcare, othering and racial discrimination, the optional character of culturally sensitive care and structural gaps in the healthcare system.

These findings have implications for both policy and practice. First, it is necessary to tackle othering, racial discrimination, and structural exclusion in healthcare. The findings show behaviours like implicit biases and cultural incompetence that enhance exclusion in healthcare, emphasizing the need for increased self-awareness and critical awareness among healthcare providers. Developing cultural competence through comprehensive training and fostering an open environment for discussing discrimination at all organizational levels are necessary steps. Integrating cultural competence education throughout healthcare curricula is essential to reflect on societal diversity and promote lifelong learning for both students and healthcare providers. Second, there must be aimed for caring encounters in a proficient healthcare system. Providing high-quality personalized care must remain the aim for healthcare providers, but the findings point out that this is not always achieved, with reports of culturally insensitive and substandard care. To improve, healthcare organizations can prioritize the relational aspect of care and support healthcare providers in delivering culturally sensitive, tailored care, ensuring the management creates conditions for effective coordination and collaboration. In addition, policy needs to guarantee inclusive, high-quality care by addressing structural exclusion, ensuring healthcare policies evolve along with patient profiles, and supporting informal carers through interventions.

To conclude, it can be stated that culturally sensitive care is essential. It is not optional, but it is a basic a basic principle in health care provision, and it needs to be the standard practice in healthcare and healthcare education. In the current superdiverse society, a diverse sensitive approach is necessary to tackle exclusion at every level, including various identities like ethno-cultural backgrounds, gender and LGBTQ+ diversity, diversity in ability and socio-economic status. Addressing uncaring encounters in healthcare, especially at the management level of care organizations and in healthcare education, is necessary. Implementation of sensitive care must occur at all levels, with the management taking responsibility to increase awareness and make culturally sensitive care the most obvious choice for healthcare providers. Finally, policy needs to address gaps in healthcare services by providing tailored services for diverse groups and support for informal carers, as the current approach is insufficient for meeting diverse and complex care needs.

Samenvatting

Dit proefschrift onderzoekt het thema cultuursensitieve zorg en bestudeert dit vanuit het perspectief van zowel zorgverleners als mantelzorgers. Deze resultaten leiden tot de ontwikkeling, implementatie en evaluatie van een educatieve module, ontworpen om het culturele bewustzijn onder studenten verpleegkunde te vergroten.

Verschillende demografische en maatschappelijke trends (zoals de vergrijzing van de bevolking met toenemende leeftijdsgerelateerde aandoeningen, een veranderde positie van de patiënt en een grotere diversiteit onder patiënten) hebben het profiel van de zorgvrager in België veranderd, wat nieuwe uitdagingen en kansen voor de gezondheidszorg met zich meebrengt (Torres, 2019).

De huidige gefragmenteerde en uniforme zorgmodellen hebben hun beperkingen bereikt en benadrukken de noodzaak voor meer geïntegreerde en cultuursensitieve oplossingen in de zorg (Wickramage et al., 2018). Cultuursensitieve zorg kan worden voorgesteld als een oplossing om uitdagingen en ongelijkheden in de gezondheidszorg aan te pakken. De implementatie ervan staat echter onder druk (Markey et al., 2018). Cultuursensitieve zorg is een benadering die wordt gebruikt wanneer patiënt en zorgverlener met verschillende etnische en culturele achtergrond met elkaar omgaan, met het doel een kwalitatieve zorgrelatie op te bouwen (Uzun & Sevinç, 2015; Young & Guo, 2020). Uit het onderzoek blijkt echter dat zorgprofessionals zich onzeker voelen en aarzelen ten aanzien van het concept van cultuursensitieve zorg (Markey et al., 2018; Roberts et al., 2007; Suurmond et al., 2010). Bovendien gaat de implementatie van cultuursensitieve zorg gepaard met verschillende uitdagingen op individueel, interpersoonlijk, organisatorisch en systemisch niveau (Eleri Jones et al., 2017; Scheppers et al., 2006; Suurmond et al., 2016).

Er werden drie lacunes in het onderzoek geïdentificeerd, welke vertaald zijn in drie onderzoeksvragen:

1. Hoe definiëren, percipiëren en verlenen zorgverleners cultuursensitieve zorg?
2. Hoe ervaren mantelzorgers van patiënten met een migratieachtergrond de professionele zorg die zij ontvangen?
3. Hoe kunnen toekomstige zorgverleners worden opgeleid tot cultuursensitieve en competente zorgverleners?

In dit proefschrift werden verschillende kwalitatieve onderzoeksmethoden gebruikt om de onderzoeksvragen te beantwoorden. Voor de eerste vraag bestond de dataverzameling in totaal uit 8 focusgroep interviews (n=46) en 15 individuele diepte-interviews met professionele zorgverleners en student zorgverleners (bijv. verpleegkundigen, artsen). Voor de tweede vraag werden 17 individuele diepte-interviews afgenomen met mantelzorgers van Italiaanse en Turkse achtergrond (11 vrouwen en 6 mannen). De derde vraag betrof het ontwikkelen, implementeren en evalueren van een lesmodule (4 uur) in een bacheloropleiding Verpleegkunde, waarbij 34 tweedejaarsstudenten Verpleegkunde betrokken waren door middel van curriculum mapping, focusgroep interviews en een bevraging.

De resultaten van de eerste onderzoeksvraag (hoofdstukken 3 en 4) geven aan dat de meeste zorgaanbieders een beperkt, stereotiep begrip hebben van cultuursensitieve zorg, en dit eerder zien als een checklist van praktische zaken in plaats van een empathische benadering. Door dit

perspectief, vormgegeven door een statische interpretatie van 'cultuur', wordt cultuursensitieve zorg vaak gereduceerd tot religieuze praktijken, vooral die van moslimpatiënten. Dit benadrukt bovendien een concept van 'anders' zijn, met een gebrek aan bewustzijn over impliciete vooroordelen en het eigen culturele referentiekader van de zorgverleners. Hierdoor kan cultuur*in*sensitieve zorg en discriminerend gedrag ontstaan. Zorgaanbieders beschouwen cultuursensitieve zorg als een uitdaging die meer inspanning en tijd vergt, en hoewel zij aangeven dat ze meer culturele kennis nodig hebben, doen zij weinig moeite om dit te verwerven, wat leidt tot onzekerheid en aannames. Hoewel sommige zorgverleners cultuursensitieve zorg benaderen vanuit een relatiegericht perspectief en dit als verrijkend beschouwen, zien de meeste individuele zorgverleners en organisaties cultuursensitieve zorg als onbelangrijk en optioneel. Initiatieven in de richting van cultuursensitieve zorg zijn vaak eerder een persoonlijk initiatief dan een mandaat vanuit de organisatie, waarbij een gebrek aan leiderschap van het management blijkt bij de uitvoering ervan.

Uit de resultaten van de tweede onderzoeksvraag (hoofdstuk 5) blijkt dat mantelzorgers van ouderen met dementie en een migratieachtergrond professionele hulp zoeken om de best mogelijke zorg te kunnen bieden. Mantelzorg brengt in de huidige tijd veel taken met zich mee. Mantelzorgers proberen een thuisgevoel te creëren door gebruik te maken van vertrouwde maaltijden, taal en omgeving om gepersonaliseerde zorg te bieden, vooral omdat standaardzorg vaak culturele gevoeligheid mist. Ondanks dat sommige zorgverleners zorg op maat aanbieden, is dit niet structureel. Bovendien is er sprake van koude en ondermaatse zorg. Deze ‘uncaring encounters’, gekenmerkt door desinteresse en ongevoeligheid, weerspiegelen bredere knelpunten in het gezondheidszorgsysteem, waaronder onvoldoende ondersteuning voor professionele zorgverleners. Mantelzorgers ervaren een toenemende last omdat zij deze hiaten van de professionele zorg proberen te overbruggen, waardoor hun rol nog uitdagender wordt.

De derde onderzoeksvraag (hoofdstuk 6) bouwt voort op de resultaten van het onderzoek bij professionele zorgverleners en mantelzorgers, en laat zien dat opleiding het culturele en zelf-bewustzijn van studenten Verpleegkunde kan vergroten. De resultaten tonen de positieve impact van de ontwikkelde lesmodule aan en suggereren dat deze een basis kan vormen voor verdere opleiding. Door zich te richten op zelfreflectie, zelfbewustzijn en het begriijpen van ongelijkheid en discriminatie kan de huidige en toekomstige training beter inzetten op het ontwikkelen van culturele competentie. Het model van 'caring & uncaring encounters' is niet geïntegreerd in het gezondheidszorgonderwijs, dat eerder de nadruk legt op technische vaardigheden. De resultaten benadrukken het belang van deze aspecten en de impact ervan op patiënten. Simulatieonderwijs, waarbij de nadruk wordt gelegd op relationele aspecten, kan het bewustzijn van studenten vergroten.

Vier rode draden komen in alle studies in dit proefschrift terug: 'caring & uncaring encounters' in de gezondheidszorg, 'othering' en discriminatie, het optionele karakter van cultuursensitieve zorg en structurele hiaten in het gezondheidszorgsysteem.

Deze resultaten hebben implicaties voor zowel het beleid als de praktijk. Ten eerste is het noodzakelijk om 'othering', discriminatie en structurele uitsluiting in de gezondheidszorg aan te pakken. De resultaten laten gedrag zien zoals impliciete vooroordelen en culturele incompetentie die uitsluiting in de gezondheidszorg vergroten, waardoor de noodzaak van meer zelfbewustzijn en kritisch bewustzijn bij zorgverleners wordt benadrukt. Het ontwikkelen van culturele competentie door middel van uitgebreide training en het bevorderen van een open omgeving voor het bespreken van discriminatie op alle organisatieniveaus zijn noodzakelijke stappen. Het integreren van culturele competentie in de curricula van gezondheidszorgonderwijs is essentieel om rekening te houden met de maatschappelijke diversiteit en om levenslang leren voor zowel studenten als zorgverleners te bevorderen.

Ten tweede is het streven naar 'caring encounters' in een bekwaam gezondheidszorgsysteem essentieel. Het bieden van gepersonaliseerde zorg van hoge kwaliteit blijft het doel van zorgverleners, maar de resultaten wijzen erop dat dit niet altijd wordt bereikt, met ervaringen van cultuur*in*sensitieve en ondermaatse zorg. Om dit te verbeteren moeten zorgorganisaties prioriteit geven aan het relationele aspect van de zorg en zorgverleners ondersteunen bij het verlenen van cultuursensitieve zorg op maat, waarbij ervoor wordt gezorgd dat het management de voorwaarden schept voor effectieve coördinatie en samenwerking. Bovendien is het aan het beleid om inclusieve, hoogwaardige zorg te garanderen door structurele uitsluiting aan te pakken, ervoor te zorgen dat het gezondheidszorgbeleid mee evolueert met het veranderende patiëntenprofiel, en mantelzorgers te ondersteunen via interventies.

Concluderend kan gesteld worden dat cultuursensitieve zorg essentieel is. Het is niet optioneel, maar een fundamenteel basisprincipe in de gezondheidszorg en hoort de standaardpraktijk te zijn in zowel de gezondheidszorg als het gezondheidszorgonderwijs. In de huidige superdiverse samenleving is een divers-sensitieve aanpak nodig om uitsluiting op elk niveau aan te pakken, met aandacht voor verschillende identiteiten zoals etnisch-culturele achtergronden, gender- en LGBTQ+-diversiteit, diversiteit in beperking en sociaaleconomische status. Het bespreekbaar maken van 'uncaring encounters' in de gezondheidszorg, vooral op managementniveau van zorgorganisaties en in het gezondheidszorgonderwijs, is noodzakelijk. De implementatie van sensitieve zorg is noodzakelijk op alle niveaus, waarbij het management de verantwoordelijkheid op zich neemt om het bewustzijn te vergroten en van cultuursensitieve zorg de meest voor de hand liggende keuze te maken voor zorgverleners. Ten slotte is het aan beleid om de hiaten in de gezondheidszorg aan te pakken door diensten op maat te bieden voor diverse groepen en ondersteuning te bieden aan mantelzorgers, aangezien de huidige aanpak onvoldoende is om tegemoet te komen aan de uiteenlopende en complexe zorgbehoeften.

List of publications and contributions

Research articles

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & Donder, L. D. (2022). Barriers and facilitators in providing care for patients with a migration background. *Journal of Clinical Nursing*. 2023 Mar;32(5-6):912-925.

Berdai Chaouni, S., **Claeys, A.,** van den Broeke, J., & De Donder, L. (2021). Doing research on the intersection of ethnicity and old age: Key insights from decolonial frameworks. *Journal of Aging Studies*. 2021 Mar;56:100909.

Tosun, B., Yava, A., Dirgar, E., Şahin, E. B., Yılmaz, E. B., Papp, K., Tóthova, V., Hellerova, V., Prosen, M., Licen, S., Karnjus, I., Tamayo, M. D. B., Leyva-Moral, J. M., **Claeys, A.** & Tricas-Sauras, S. (2021). Addressing the effects of transcultural nursing education on nursing students' cultural competence: A systematic review. *Nurse Education in Practice*. 2021 Aug;55:103171.

Claeys, A., Berdai Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2020). Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals. *Journal of Transcultural Nursing*. 32(5), 484-492..

Berdai Chaouni, S., **Claeys, A.** & De Donder, L. (2018). How to (qualitatively) involve older people with dementia and their informal carers with a migration background in research? Insights from a longitudinal project in Brussels. *Proceedings European Congress of qualitative inquiry*

Books

Berdai-Chaouni, S., & **Claeys, A.** (2022). Démence chez les personnes agées issues de l'immigration. Garant / Maklu: Antwerpen. 252 p. ISBN 9789044138962.

Berdai-Chaouni, S., & **Claeys, A.** (2021). Dementie bij ouderen met een migratieachtergrond. Garant / Maklu; Antwerpen. 241 p. ISBN 9789044138276.

Gove, D., Georges, J., Rauf, M., Broeke, J., Jongsma, K., **Claeys, A.**, Berdai, S., Hellström, I., Tromp, K., Porteri, C., & Watchman, K. (2019). Overcoming ethical challenges affecting the involvement of people with dementia in research: recognising diversity and promoting inclusive research. Alzheimer Europe.

Yentur, A., **Claeys, A.**, & Claes, B. (2016). Werkboek cultuursensitieve zorg. Politeia: Brussel. 128 p. ISBN 9782509026903.

Book chapters

Berdai Chaouni, S., **Claeys, A.**, Hoens, S., Pan, H., & Smetcoren, A. . S. (2021). The fallacy of migrants-culture preventing access to care in later life. I. In Migration, Equality, Racism: 44 opinions (pp. 141-148). VUB press: Brussel. 274 p. ISBN 9789461171023.

Berdai Chaouni, S., **Claeys, A.**, & De Donder, L. (2019). Dementie bij ouderen met migratieachtergrond. In Kleine gids voor dementie (VIEWZ ed., pp. 191-202). Vanden Broele: Brugge. 245 p. ISBN 9789049617875.

Valorisation papers

Berdai Chaouni, S., **Claeys, A.**, & De Donder, L. (2019). Geloof beïnvloedt hoe iemand dementie beleeft. *Sociaal.net*. https://sociaal.net/achtergrond/geloof-beinvloedt-hoe-iemand-dementie-beleeft/

Berdai Chaouni, S., & **Claeys, A.** (2018). Dementie speelt verstoppertje bij Ali en Antonio. *Sociaal.net*. https://sociaal.net/opinie/onderdiagnose-dementie-ouderen-migratie-achtergrond/

Berdai Chaouni, S., & **Claeys, A.** (2018). Older migrants have the right to be treated with respect: respect of their age, and respect of their culture. *Ageing Equal, AGE Platform*. https://ageing-equal.org/the-othering-of-oldermigrants-in-care/